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Examination and Assessment of U.S. and U.K. Strategies and Approaches for Addressing Racial/Ethnic Minority Health Concerns

Executive Summary

Background

Both the U.S. and the U.K. share many similar challenges in addressing the health concerns of racial/ethnic minorities. In response to mutual interests of the U.S. and the U.K. to improve the health of their respective racial/ethnic minority populations, a cooperative effort was undertaken by leadership of the Office of Minority Health (OMH), Office of Public Health and Science (OPHS) in the U.S. Department of Health and Human Services (DHHS) with the British Department of Health to identify and draw upon the experiences and lessons learned from both countries and to develop an agenda for closer U.S.-U.K. health services collaboration in meeting the health needs of these populations. The focal point of this collaboration was a bi-national conference, "Health Gains for Black and Minority Ethnic Communities," held in the U.K. September 16-19, 1997, during which health policymakers and others committed to and leading the way on race and health issues came together to share and discuss strategies and approaches used in each country to address minority health in general as well as a range of themes and issues specifically. An important aspect of this international cooperation is the involvement of key partners in both the public and private sectors and at national, State, and local levels.

Conference participants identified the following areas as priorities: improving access to services; improving research on minority health; empowering minority consumers; improving data collection; and enhancing leadership and organization in minority health.

The highlight of the conference was the signing of a joint statement of intent between the U.S. Department of Health and Human Services and the Department of Health of the United Kingdom to collaborate on improving minority health. Following the conference, U.S. and U.K. workgroups identified areas for collaboration and developed action steps. The core areas for initial collaboration are improving access to culturally competent health services and developing the voice of our communities and grassroots sectors.

The conference focused on six theme/issue areas: (1) Provider/Purchaser Issues: Obstacles to Equality; (2) Quality of Care: How Do We Assure; (3) Developing Primary Care; (4) Population Size and Characteristics-Data Surveillance; (5) Research and Development; and (6) Informal Care and Empowerment of Minority Communities. For each of the six (6) specific conference themes/issues OMH required the services of selected health experts to: 1) develop an issue paper focusing on U.S. strategies and approaches for addressing the theme/issue relative to minority health; 2) attend and/or participate in the Conference to collect additional information and perspectives about U.S. efforts on the relevant theme/issue and, more importantly, to gather as much information as possible regarding U.K.efforts on the same theme/issue; 3) *possibly to* present some of the information in the issue paper at the relevant workshop during the Conference; 4) develop a comparative analysis of the strategies and approaches undertaken by the two countries in an attempt to identify strengths and limitations, what works/does not work and why, best practices, lessons learned, opportunities for future collaboration, and recommendations for future action; and 5) develop a post-Conference paper that incorporates the comparative analysis into an integrated piece suitable for broader HHS distribution and possible publication.

SUMMARY OF ISSUE AREAS' FI NDINGS AND RECOMMENDATIONS

Developing Primary Care - Race, Ethnicity, Class, and Culture

Several studies have shown that the highest rates of poverty are concentrated among the same U.S. subgroups of non-White people who are also those with disproportionately worse health status. This health status of racial and ethnic minorities in the U.S. is a function of the very structure of the U.S. society. In this structure, racism and economic inequality are institutionalized.

The health care delivery system is no different than all other components of the U.S. social structure in terms of its reaction to race and class. In fact, health care in the U.S. is a multi-billion dollar industry that, in and of itself, is reflective of race and class divisions within society. Access to regular, ongoing primary health care in the U.S. is contingent upon the possession of health insurance, whether public or private, which is directly connected to one's employment or lack thereof. This is a problem for significant numbers of minorities who tend to have higher rates of unemployment. Eligibility for Medicaid, the public insurance available to the poor, is based on stringent guidelines for means testing, which have now become even more rigorous as a result of welfare reform.. The situation leaves large numbers without health insurance. Estimated to be anywhere from 40 to 75 million, the uninsured are actually two groups: the never insured and the sometimes insured.

U.S. health care delivery and policy targeting minorities has historically employed two opposing but similar approaches in terms of outcome. In one approach, the importance of race is downplayed or negated in health analysis. In the other approach, the claim is made that minorities experience poor health and premature death because of pathological behavior that includes a choice to smoke, drink heavily, consume the wrong foods, engage in unprotected sex and violent behavior, and lead sedentary lifestyles.

It is important to note that this connection between health status, race and ethnicity, and socioeconomic status is not unique to the United States. This is a global condition that is well documented in the international health literature. The National Health Service (NHS) in the U.K. was designed largely to serve a homogeneous White population. So though the U.K. has a system of universal health access, minorities there—as is the case for minorities in the U.S.— do not always receive culturally and linguistically appropriate care.

Both the U.S. and the U.K. are aware that any improvement in the health status of racial and ethnic minorities must flow from a strong research agenda. To deliver effective primary care services to the entire population of both countries, we must first acknowledge some critical factors. One is that given what we now know about the progressive nature of health deterioration over time and how this is influenced by behavior change, we must recognize that medicine has failed us in terms of its ability to help us change behavior. This is not to detract from the amazing life-saving technological advancements over the last 50 years. But the challenge of both countries is how to best bring about behavioral change, considering the extent to which health behavior and practices are influenced by culture.

In many ways, the development of primary care as a national health services delivery strategy that meets the needs of everyone demands a new kind of research—one that is population driven. Research and needs assessments of minority communities must be conducted using totally new paradigms. The community must be involved in planning the research. Community members must be trained to serve as point persons in data collection, as they are much more likely to obtain data that is accurate than the outside researcher. And as data is analyzed, minority groups being studied must help interpret data. This type of research is beneficial because health education flows in two directions rather than one.

Population Size and Characteristics-Data Surveillance - The Quality of Racial Data

Race is routinely used in an uncritical manner with little attention given to the underlying problems of measurement that exist for the current racial categories. These problems have a significant effect on the quality of U.S. health data .The numerator for the officially reported death rates in the U.S. come from death certificates. There are reliability problems with the assessment of race that suggests there is an acute problem of undercounting racial and ethnic status for American Indians/Alaska Natives, Asian Americans and Pacific Islanders (AAPI), and Hispanics.

A major source of this undercount is the discrepancy between race as observed by an interviewer and self-reporting by respondents. Between 1957 and 1977, race was determined by interviewer observation in the Health Interview Survey. In 1978, the year in which the measurement of race was changed in that survey, racial information was collected both by interviewer and self-report.

A study of a large national population found that one-third of the U.S. population reported a different racial or ethnic status one year after their initial interview. A study of a large national population found that one-third of the U.S. population reported a different racial or ethnic status one year after their initial interview. The most dramatic evidence of change in self-identification comes from analyses of trends in the American Indian population over time. Between 1960 and 1990 there was a six-fold increase in the Indian population. This dramatic growth cannot be explained by biological growth or international migration. It also appears to reflect a change in self-definition, with more adults of mixed ancestry identifying themselves as American Indian. This shift in self-identification into the American Indian population is more common at younger ages.

The degree of identification as Indian may not be very strong for many of these "new Indians." Most persons reporting American Indian ancestry did not report American Indian race. American Indian identification for this group may be optional and contextual, depending on the form of the race question, economic incentives for being Indian in some states, and increased willingness to self-identify as American Indians. Given current rates of intermarriage of Indians with persons of other races, there is likely to be continued rapid growth in the pool of persons who will be of some Indian ancestry, but for whom this ethnic identification may not be consequential.

The discussion of establishing the racial status of American Indians raises the more general problem of establishing the race of an individual whose parents are of different races. Birth certificates in the United States have never listed the race of the child, but they include the race of both parents. Prior to 1989, the National Center for Health Statistics (NCHS) used this method to determine the race of children whose parents belong to different races: If the father was White, the child would be given the race of the mother. But if the father was non-White, the child would be assigned the race of the father. If one parent was Hawaiian, then the child was Hawaiian. Thus, unlike the assignment of race for all other racial groups, the child would be White only if both parents were White.

NCHS no longer reports vital statistics by the race of the child, but reports all birth data by the mother's race. However, the Indian Health Service continues to consider a child as Indian if either the mother or father is American Indian, and there is considerable discrepancy in the publication of infant mortality rates by race of the child or by race of the mother.

The question of how to classify persons whose parents are of different races continues to be a hotly debated policy issue in the U.S., with some groups pushing for further changes in the Office of Management and Budget's racial standards, which were revised in 1997. Current trends of interracial marriage suggest that this classification question will apply to an ever-increasing proportion of the population**.**

Racial Data in the United Kingdom - The 1991 Census of England and Wales was the first to utilize the question on ethnicity. Seven preassigned codes were used in the census. These were: White, Black Caribbeans, Black Africans, Indians, Pakistanis, Bangladeshis, and Chinese. An additional 28 categories were developed in the census based on write-in responses under the "Black other" and "any other" ethnic group categories.

Several recent health surveys in the U.K. have also included measures of ethnic group membership. The Health Survey of England, which began in 1991 and focuses heavily on cardiovascular disease, has included racial and ethnic data. Similarly, the General Household Survey of about

15,000 households per year has included data on ethnicity and country of birth in recent years. The survey includes measures of self-reported illness, both chronic and acute, as well as of risk factors and socioeconomic status. Data on patient care in the U.K. is available through the Hospital Episode Statistics system, which collects data on all inpatient and outpatient hospital visits.

In 1995, ethnic categories were included in this data system. It will thus become possible to examine rates of particular diseases, surgical interventions, severity, etc., by ethnic group status. Ethnic status is not collected on death certificates, and it would require an Act of Parliament for the inclusion.. But country of birth has been collected on death certificates since 1969 so that it is easy to examine mortality rates for first generation immigrants. Similar to the U.S., there is a linked infant birth and death file in the U.K. But unlike in the U.S., ethnicity is not collected at the time of registration of birth..

Informal Care and Empowerment of Minority Communities

"Informal care" is operationally defined as "the practice of alleviating distressful physiological and psychological dysfunctions through all other (e.g., traditional healers, family members, self, etc.") using measures that do not require a physician's prescription or intervention (e.g., lifestyle modifications) typically outside of formal, institutionally based care mechanisms (e.g., homes and communities). Informal care is a significant force in health maintenance, health promotion, and disease prevention. In the U.S. at least one-half of racial/ethnic populations use informal care.

Informal care may be used more frequently among racial/ethnic minorities because of their long standing cultural and traditional significance and also because barriers to accessing formal care may be more prevalent among racial/ethnic minorities. Barriers to assessing formal care may include cultural, financial, geographic (transportation), organizational, and linguistic barriers. Hence, informal care may be the only reliable care that racial/ethnic minorities receive. However, a valid documentation on the prevalence of informal care practices within any community is difficult because of the broadness of its scope and the logistical barriers in conducting such surveys in racial/ethnic communities

"Empowerment" of racial/ethnic minority communities is the right for minority populations to determine their own destinies. In the U.S., racial/ethnic minority populations are Blacks, Hispanics, Asian Americans or Pacific Islanders, and American Indian/Alaska Native. These classifications are based upon self-report; in the U.K., the black and minority classifications are based upon countries of birth rather than self-reported racial/ethnic identities. Empowerment of these communities is important both demographically and historically. In demographic terms, racial/ethnic minority populations are increasing at higher rates than the majority population in the U.S. and hence, the health status of minorities will become the health status of the nation in the next half century. Historically, racial/ethnic minorities have not been empowered. As a consequence of the 1985 *Secretary's Task Force Report on Black and Minority Health*, Federal measures to address disparities in the health status of minorities were initiated. In March 1994, the U.K. Government initiated the Ethnic Health Unit within the National Health Services. These measures are not mature enough to evaluate their impact. However, progress in implementing measures to empower minorities in the U.K. are underway.

In the U.K. black and ethnic populations constitute six percent or an estimated three million people in England and Wales (NHS, 1995). Their patterns of morbibity and mortality differ from White majority population and the within-black and ethnic populations differences are also quite prominent.

It is clear that at the individual and social levels in both the U.S. and the U.K., overcoming linguistic and cultural barriers is fundamental. As the population become increasingly diverse, these issue of empowerment will become even more complex.

Empowering minority communities through informal care may be most culturally appropriate approach for improving the health status of minority populations. Informal Care is pervasively used by minorities and its potential in improving the health of minorities has been under-estimated and under-utilized.

Minority health professionals are individuals most likely to be the impetus to empower their own communities for health improvement. Hence, increasing the number of trained minority health professionals is one strategy that must be pursued. They are the ones most like the racial and ethnic communities who need to be targeted because of their disparate health status.

With increasing medical care costs and with frustration with Western medical care institutions, more and more people are seeking informal care. The trend is such that formally trained Western health professionals must acknowledge their patients' use of informal care. Physicians are being advised to inquire as to their patients' use of informal care. However, our aim should be to eliminate racial/ethnic differences in health status in both the U.S. and the U.K. This, in fact, is a proposed goal for the U.S. Healthy People 2010 Objectives for the Nation. The level of health status that can be achieved for the majority should be attainable by all, regardless of racial/ethnic background.

Specific recommendations include:

1. Conduct surveys to document the prevalence and patterns of informal care usage among racial/ethnic populations in both the U.S. and the U.K. Such surveys should be conducted in such a way to overcome barriers associated with participation in previously conducted surveys, e.g., conducting surveys fact-to-face, engaging racial/ethnic members of the surveyed communities to overcome cultural and linguistic barriers to survey participation, using concepts and not just literal translations.

2. Identify cases where healthful outcomes occurred exclusively through formal care practices. Conduct case studies and case-control studies to assess factors associated with the efficacy of such practices in both the U.S. and U.K.

3. Collect both U.S. and U.K. data (including oral histories and literature searches) of successful cases of empowerment in minority communities. Identify factors associated with their success including the role of their cultures and their adaptation to their adaptation to their environments that enable their success.

Quality of Care: How Do We Assure - Comparative Analysis of Problems, Strategies, and Approaches

Given that this was the first conference to bring together health providers, administrators, and researchers from both the United States and the United Kingdom to specifically address the issues related to the quality and quantity of health care received by minority populations, there was much enthusiasm, sharing and interest in collaboration exhibited by the conference participants. The conference deliberations focused on the similarities and differences between the U.S. and U.K. health care systems in terms of providing accessible and acceptable care for minority populations. Clearly there are differences in the size, origin, culture, language, and experience of the minority populations of these two countries as there are differences in the health care delivery systems. It was noted that the overarching difference in access to health care between the U.S. and the U.K. was that in the U.K. the problem was related to lengthy waiting times while in the U.S. the problem revolved around the very large and growing population without health insurance coverage. However, even though the U.K. may have fewer financial access barriers for their minority populations, both countries need to mount interventions to make health services more acceptable and relevant for all of their populations. Despite these differences, a great number of similarities were also noted. All present believed that through the exploration of these similarities and differences we could achieve useful models to achieve a more favorable health status for all minority populations.

Participants noted that both countries have experienced a slow policy formulation process for addressing their minority health issues. In the U.K. it was noted, Black and ethnic minorities have resided in the country since the 1950s yet the relevant National Health Service policy originated in the 1980s. In the U.S., relevant policy followed the introduction of ethnic and racial minorities by hundreds of years.

It was unanimously observed that both countries needed to address the significant problems associated with not having a culturally representative health professions workforce. It was noted that achieving a more representative health workforce could make health services more acceptable and relevant for ethnic and racial minorities and could also help ameliorate the underlying socioeconomic basis of minority health concerns. A high priority for both countries is to significantly increase the participation of minorities in health policy-making bodies and to provide appropriate training for all of their health policy makers.

Another element of representativeness revolves around the need to increase the numbers of minority populations involved in clinical trails and other health investigations so that we may have the most timely and scientifically rigorous treatment protocols for all populations groups. It was observed that in both countries, not all minorities had negative health outcomes. Indeed it is through the exploration of divergent health outcomes both positive and negative that we can better understand the underlying processes. It was reported that in the U.K. they were adopting minimum health data sets to help evaluate how minorities use health services. The two countries share a need for a national research strategy and a need to train and involve more minority health researchers. Several present also felt that we needed to more effectively link public health research with social policy research. Clearly, both countries need to accurately forecast minority populations so that we do not plan inappropriate services. It was observed the health trusts in the U.K. have a greater opportunity to influence health professions schools when they start negotiating their contracts with schools by comparing how their graduating classes compare with the future needs of the populations to be served.

Accessible, acceptable, and appropriate health care is only possible if we properly engage the minority community. The relatively poor health of minority populations in both countries is largely attributable to the poor socioeconomic status of those groups. Both countries need to expand their emphasis on involving the community in the design of their health services. It is imperative that both engage in coalition-building so as to develop partnerships with the community. Both countries need to target their outreach to the minority community.

The U.K. and the U.S. also share the need to mainstream the minority agenda to assure that it not serve as an afterthought. Toward this end, conference participants noted the need for a focal point within their government for minority health concerns. While this may be organized differently between the two countries (for example, the Office of Minority Health in the U.S. and the Department of Health office of the Advisor on Ethnic Minority Health in the U.K.), it is essential that the corresponding office have access to and the confidence of the highest national health policy maker.

Lastly, it was the consensus of the conference that the United States and the United Kingdom need to continue to support and consult with each other so as to develop more effective health policy for all.

Research and Development

While the strategies, approaches and initiatives are varied at the federal, state and local level, there are some uniform strengths and weaknesses noticeable in all three. The fact of concentrat-ing resources on minority health research has been a strength. Absent these efforts, we would know even less than we do today. The weaknesses, however, have been many. Senior researchers more competitive than junior. While this is a normal fact of academic research progression, the demographic fact is also that minority researchers tend to be junior, less experienced, and often in non-tenure track positions.

Research university based projects are more competitive than projects based in non-research based universities. Minority researchers are often based in smaller universities, or even in non-university environments. They simply function with less research support and with fewer colleagues than their competitors research universities. The result of these academic patterns is that much minority health research is performed by non-minority researchers. While in itself, this is not necessarily a fatal flaw, a major limitation is that new theoretical models have not been as quick to emerge as that would be if there were greater theoretical diversity involved as a result of greater researcher diversity.

While the involvement of private sector, corporate sponsorship is new and a welcome respite from the constant cut-backs from the public side, it is not an unmitigated blessing.
Private research on minority health tends to be more market research, drive more by an interesting penetrating the markets and enrolling subscribers, and less to understanding the underlying health processes and dynamics. In addition, at times privately sponsored research is proprietary to a single provider group, and not readily shared or made publicly accessible.

In summary, the strategies and approaches to research minority health in the U. S. has been to assume: (a) that white, non-Hispanic health profiles and behaviors are the norm; (b) that minority populations’ health profiles and behaviors invariably depart from the norm, in negative ways; and (c) that research efforts focus on identifying and explaining negative deviances from the white, non-Hispanic norm.

The major difficulty with the general trend in minority health research, as summarized immediately above, is that the white, non-Hispanic population is no longer the statistical norm. In los Angeles County (a local entity with 9.1 million residents), the Anglo population is only 35% of the county’s total. As indicated earlier, in most major states, the white population will be a minority within the next decade or two. The notion that the White population profile sets the statistical norm against which other groups deviate will be unworkable early in the 21st century.

While a federal-level “gold standard” of ethnic identifiers exists, it has not been uniformly implemented. A necessary first strategic step will be to have it fully implemented at a federal, state and local level. Within that mandate, the skyrocketing intermarriage rates will require that new categories be developed which will allow for multi-racial children to be properly accounted for.

The inability of current theoretical models of minority health to explain the “Latino epidemiological paradox” points to a need for new theoretical models that can better capture the dynamics and processes of minority health. The number of minority research projects funded by federal Institutes is still quite small. A sufficient knowledge base has to be built, and that can only be the result of large number of projects involving a large number of researchers.

The quest for new theory will be greatly accelerated by the preparation of greater numbers of minority researchers. The training in research will need to be focused on population-based studies, so that the statistical norms for different minority groups may be understood, and outlier sub-populations be placed in proper perspective. In addition, the training will need to include the development of new conceptual models and theoretical paradigms to better explain variance in health status between the different minority groups, and the sub-group variance within each group.

With the exception of Asian American researchers, the growth of minority researchers has not even kept pace with minority population growth. Current policies limiting the use of Affirmative Action considerations in admissions to graduate and health sciences schools may negatively affect the preparation of minority scholars and researchers.

International Comparative Studies

While minority health has long been considered strictly domestic issue, the increased globalization of economies and the increased immigration flows from non-European regions suggest that theoretical breakthrough may now come form international comparative studies.

Formal workshop presentations, and informal discussions allowed an interchange of experiences about research and development issues in minority health. Work in the U.S. is much further down the learning curve than in the U.K. However, work in the U.S. has had to enter many blind allies, and overcome many obstacles. These were shared with U.K. colleagues, in the hopes that they might avoid problems and pitfalls encountered in the past 35 years' experience researching minority health in the U.S.

The U.S. strategy, for 200 years, has been to identify certain racial and ethnic groups in public data sets. Only recently in this lengthy history (since the mid-1960s) have inter-group disparities been seriously researched with an attempt to understand the dynamics of discrepancy. In the U.K., the strategy has been, until recently, a race-blind approach, where data were not collected on particular racial/ethnic groups. The growth in size of the minority population has led to an interest in creating race and ethnic-specific data sets, but this has had to occur "in addition to" the general data collection efforts.

One of the founding principle of the National Health Service was the provision of health services to all on the basis of clinical need, regardless of ability to pay. The move away from a completely nationalized system to a "managed competition" system, whereby local Authorities contract for services, has raised the issue of the relationship between ethnicity and health in particular authorities. The policy was to provide data on this relationship to assist the Authorities in developing activities appropriate for a local area.

The U.S. operates on a market-driven system, with public services being considered the "provider of last resort". Until the Civil Rights Movement, racial and ethnic identifiers were more often used to exclude service utilization. Since the mid-1960s, changes in the medical care industry have led to the development of large-scale provider corporations (e.g. HMOs, IPAs, etc.) with more of a focus on populations than in the past. Interest in ethnic health outside the public sector is increasingly driven by market forces rather than principled dedication, but serves the same end: large corporate providers need to learn how to market and provide services to a diverse population.

While U.S. Census data have been meticulous in identifying some racial/ethnic groups over a period of time, U.K. data have not had a lengthy history of similar data collection. Without population-based demographic data, rates cannot be computed. A special census was undertaken in the U.K. in 1991, by the Office of Population Censuses and Surveys to provide both population estimates and population characteristics.

Uniform comprehensive racial identifiers have been lacking in US data until recently. While such indicators do not always distinguish between sub-groups (e.g. Koreans and Vietnamese instead of just Asian/Pacific islander, or US born Mexican and Salvadoran immigrant instead of just Latino) nor are they uniformly applied everywhere (e.g. Florida still does not code for Hispanic) there are sufficient data to provide large-broad brush-stroke portraits of health profiles. The use of such indicators is new in the UK, and even broad-brush stroke portraits are in their initial phases.

In both the U.S. and U.K., there is still considerable confusion about the proper terms to use for different groups, and their proper operationalization. The U.S. has in the past been meticulous in identifying a few specific racial groups, However, the largest, fastest growing group is Latino, which is not necessarily a racial group. Hence, there is still confusion about terminology and operationalization for this group. In addition, the increase in intermarriage rates have outstripped the ability of agencies to identify the offspring of such unions.

In the U.K., data are kept for country or area of origin, but not necessarily for racial group. Thus, immigrants from East Africa may be largely East Indian in a cultural sense, while those from West Africa may be largely Black African, but white populations resident in those areas would also be included in the two categories. The terms used in both countries may allude to: race, ethnicity, and country/area of origin. Epidemiologically, these may be very different types of populations.

While there are many methodological issues still being resolved, there has been a push in both countries to create and release timely data. The report Ethnicity and Health in England was released, knowing that there were many data gaps. Likewise, data in the US on minority health are released at the federal and state level, with the full realization that there are many holes. The interests of society are better served by wide dissemination of data, even if spotty. Certainly policy decision are better served by some data rather than by no data.

Recommendations For Future Actions

Black and minority populations are currently 6% of the U.K. population. It was pointed out that in 1950, minorities were only a slightly larger percent, 9%, of the U.S. population. The demographics in the U.S. have changed that so that nearly 1 in 4 Americans are minority, and projections are that by 2050, the White Non Hispanic population will be a minority in the country. It is quite possible that there will also be sizeable minority growth in the U.K.

Some districts and boroughs in the U.K. are already heavily black and minority. Brent and Newham were 45% and 42% minority, respectively. There are twenty districts and boroughs that are 19% or more minority. In the U.S., many cities are already predominantly minority, and early in the 21st century, major states such as California and Texas will have majority-minority populations. The two countries have much to teach one another about research and development in the area of minority health.

Obstacles to Equality Issues for Purchaser and Provider

The United Kingdom and the United States share many characteristics, from a common dominant language to ethnic and cultural diversity of their populations. Both the United Kingdom Department of Health and the U. S. Department of Health and Human Services share a deep concern about and face health care issues of the racial and ethnic minority populations in their respective countries. This diversity poses unique challenges to the health care systems and the purchasers and providers in particular in each country. The purchaser must design systems that are flexible enough to adapt to different populations and providers must not only master an infinite amount of medical knowledge but also must be culturally competent in a wide array of cultures so as to effectively communicate and treat patients from these cultures.

The timing of the U.K. conference, Health Gain for Black and Minority Ethnic Communities: International Conference Between the U.K. and the U.S., was excellent. It is on the verge of the 50th anniversary of the National Health Service (NHS). The NHS is a good system but is drastically underfunded. 5.4% of the GNP was okay fifty years ago, but the system has not kept up with the increasing costs of technology and medicine. It does have universal access that covers the basic care needs for everyone. It has a primary care (general or family practice) focus that is more cost-effective than the speciality care focus seen in the U.S. It has centralization of care, so there is less duplication of services, and administrative costs are less. Its main negative is its lack of funding. There are long waits for specialty services and procedures. While in the U.K., one surgeon told the Health Authority to cancel those below a certain point on the list, as it was unrealistic that they would receive their care with the current funding. Racism is still prevalent. There are a surprising number of minorities in the U.K. The National Health Services Ethnic Health Unit Report, “Ethnicity and Health in England,”[16] estimated it at six percent of the population or about three million. They are primarily an urban population. There are not only complaints of racism, but it is also uncommon to see providers who are culturally competent. There has been no effort to fund programs that would encourage resident minority young people to seek medical careers. Even though the NHS is now fifty years old, it was not until 1993 that a report was generated — “Ethnicity and Health: A Guide for the NHS”. It was not until 1994 that the NHS Ethnic Health Unit was formed. These are steps in the right direction, but they come quite late in the history of the NHS.

In evaluating the U.S. system, it fares no better, and although there are similar shortcomings, it fails in different areas as well. There is generally rapid access to high-tech speciality care. The down side is that this is a very expensive approach. Although primary care has made some gains, it is still not in a strong enough position to significantly lower health care costs. President Clinton's failed effort to achieve universal access to health care did prove how strong the health insurance and specialist provider lobby was. The specialty approach and large number of health plans causes fragmentation of health care, duplication of services, and tons of paperwork. As in the U.K., cultural competence is low. There are, however, great programs at The National Institutes of Health, The Centers for Disease Control and Prevention, and at many medical schools, universities, and teaching hospitals that train minority providers and researchers. They are already culturally competent, and research has shown that they are much more likely to care for under-served populations.

The Conference was the first step in allowing our systems to learn from each other. Hopefully this endeavor will continue long into the future.

Recommendations

We can learn a lot from the U.K. health system. Although grossly underfunded, it has the basics in place, i.e. care focus and universal access to care. It, too, suffers from lack of cultural competency and racism, but training can go a long way to alleviate that problem.

Funding programs to train health care providers and personnel costs money but will improve the quality of care for minorities as well as nonminorities because it teaches respect for the individuality of each patient regardless of race.

The U.S. system is specialty oriented and costly, and despite the high cost of health care, there is not universal access. There is excellent funding for training of minorities at the National Institutes of Health, the Centers for Disease Control and Prevention and at most universities, medical schools, and training hospitals. Cultural competency training is also badly needed in the U.S.

The ideal health care system would have universal access for basic health care with a primary care focus and would be funded somewhere between the U.K. and U.S. health expenditures. High tech, expensive, experimental care would be limited severely to lower costs, and funding for training of primary care providers would be increased. Cultural sensitivity training would be mandatory, and funding for minority students, who are more likely to go to underserved populations, would be increased. Research would have a more practical primary care approach that would have a better chance of having a positive impact on the health of our nation now. Currently, most research at NIH, our largest research funder, is mostly in the basic, not applied, sciences and is very esoteric.

QUALITY OF HEALTH CARE FOR ETHNIC/RACIAL MINORITY POPULATIONS

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The Health Professionals

It has often been stated that the United States does not have a system of health care but rather has numerous systems depending upon where one lives and one's social and economic position. Historically, there have been many reasons why health care availability has been so varied in the United States. The availability of health personnel such as physicians and nurses has always been uneven throughout the country. Since there is no national system of health professions education, students compete for admission to the public and privately-owned health professions schools of interest to them. Most often these schools have been situated in large cities where the high volume of hospital admissions supports the necessary clinical educational program. Historically, U.S. physicians have set up their clinical practices in proximity to where they have received their graduate medical training. As a consequence, the United States has always experienced difficulties in attracting sufficient health providers to rural areas and the impoverished inner city urban areas.

A second factor which has had a significant impact on quality of health care has been the cost of a medical or other health professions education. With private medical schools charging tuition rates in excess of $20,000 per year, medical education has become the education of the privileged and the financially indebted. Graduates of these schools are coming into practice with very large financial debts for their education and many choose to pursue the most profitable practice rather than the one offering the greatest satisfaction or contribution. With the exception of several government funded financial assistance programs for health professions students, caring for the poor ethnic/racial minority populations has often not been seen as compatible with paying off large educational debts.

Another factor which can impinge on both the availability and acceptability of health care is the degree to which the nation's health professions students reflect the ethnic/racial composition of the general population. This is an area where the United States has failed badly for a very long time period. As recently as the early 1970's, the United States had one white, non-Hispanic physician for every 530 white, non-Hispanics in the general population; had one African American physician for every 4,100 African Americans; one American Indian physician for every 13,800 Native Americans; and one Mexican American physician for every 25,000 Mexican Americans. Consequently, the United States has always experienced tremendous difficulties in communicating with and understanding the health beliefs and practices of ethnic/racial minority populations.

First-year enrollment in schools of medicine has risen for minority students from 4 percent of all students in 1968-69 to 26 percent in 1988-89 (Association of American Medical colleges, Annual Fall Enrollment Surveys).

In 1968-69, African American students accounted for under 3 percent of first-year medical school enrollees. After peaking at 7.5 percent in 1974-75, the rate dropped to 7 percent and has been fairly stable since then at around 7 percent.

In 1968-69, there were only 23 Hispanic students, 0.2 percent of all first-year medical students. The proportion increased rapidly to 2.7 percent by 1974-75 and has leveled off during the 1980's at around 5.5 percent of all first-year medical students.

American Indian students continue to comprise the lowest proportion in medical schools, increasing from 0.1 percent in the late 1960's to around 0.5 percent in 1988-89.

The most dramatic change has occurred among Asian students. Their growth in medical school enrollments began in the mid-1970's, with proportions doubling every few years from 2 percent in 1975-76 to 4 percent in 1981-82 to 9 percent in 1986-87. By 1988-98, fully 12 percent of first-year medical school enrollees were of Asian descent.

In 1988-89, the medical school enrollment rate (the number of first-year students per 100,000 persons 15-24 years of age) was nearly five times higher for Asian students than for white students (187 compared with 40). The rates for Hispanic, African American, and American Indian students were considerably lower (26, 22, and 20, respectively).

In addition to the fact that the United States has not enjoyed a representative cadre of health professionals, until relatively recently, few health professional schools offered sufficient curricular content regarding the health needs, beliefs and practices of ethnic/racial populations. As a consequence, few physicians, nurses, dentists, etc. are adequately prepared as a result of their education to provide health care to minority populations in a culturally competent and relevant manner.

The Population

From its inception, the United States has had a population of diverse backgrounds.

The different ethnic/racial populations in the United States bring many challenges to the health professional. In addition to the differences in health beliefs and practices that these populations possess, there are differences in health needs that arise out of unique characteristics of these populations. These unique characteristics can include differences in genetic makeup, occupational exposure, socioeconomic resources, and nutrition among others.

The ethnic/racial minority populations in the United States have been increasing at far greater rate than the white non-Hispanic population. Since 1980, the Asian population has increased by 70 percent to 6.5 million in 1988. The Hispanic population has increased by 34 percent to 19.8 million, while the American Indian population has grown by 19 percent to 1.7 million. The African American population in the United States has increased by 13 percent to 30.2 million while the white non-Hispanic population has increased by 6 percent reaching 207.4 million in 1988 (U.S. Bureau of the Census, 1990).

Growth of the Hispanic population has resulted equally from immigration and fertility. Close to 40 percent of all immigration during the 1980’s has been from Latin America. From 1980 to 1988 the Hispanic population increased from 6.5 to 8.1 percent of the total population. The rapid growth of the Asian population is attributed largely to immigration. Since 1980 45-50 percent of the nearly 600,000 annual legal alien immigrants have been from Asia. (U.S. Bureau of the Census, 1990).

Relative to financial access to health care, the racial and ethnic variation in socioeconomic status has been large. In 1988, 32 percent of African Americans and 27 percent of Hispanic Americans had incomes below the poverty level compared with 10 percent of non-minority individuals and these differences have remained largely unchanged over the past decade (U.S. Bureau of the Census, 1989). In 1979, 28 percent of American Indians were living on incomes below the poverty level as were 13 percent of Asians (U.S. Bureau of the Census, 1980).

Among children and families, these differences in poverty rates are even more pronounced. In 1988, 44 percent of African American children and 38 percent of Hispanic children under 18 years of age were living in poverty compared with 14 percent of white children. Furthermore, 52 percent of African American families and 26 percent of Hispanic families with children below the age of 18 years were headed by a female with no husband present compared with 16 percent of non-minority families (U.S. Bureau of the Census, 1989).

The vital health statistics systems in the United States have historically presented problems relative to producing valid and reliable mortality statistics for some ethnic/racial groups (Trevino, 1982). Nonetheless, current mortality data revealed that Asians in the United States had the lowest mortality rates in 1988. Among persons under 45 years of age, African Americans and American Indians had the highest death rates with the greatest African American-white and American Indian-white rates occurring at ages 25-44 years (2.5 and 1.8, respectively). With increasing age these differences narrowed and for persons 65 years and over, African American-white differences were minimal and white death rates exceeded those for American Indians. In 1988 death rates at ages 15-24 and 25-44 years for the Hispanic population exceeded those for white persons by 19 and 24 percent, respectively. Among persons ages 1-14 years and 45 years and over, death rates for Hispanic persons were similar to or lower than those for white persons in 1988 (Health United States, 1990).

Health Insurance and Other Factors Associated with Access to and Satisfaction with Health Care

Lack of health insurance has been found to be associated with lower health care access measures (Hubbell et al., 1989; Freeman et al., 1987; Lefkowitz and menheit, 1991; and Trevino et al., 1996). On the whole, Hispanics have the lowest financial access to health care of any ethnic/racial group in the United States as measured by their rate of health insurance coverage. Data from the 1980 National Health Interview Survey revealed that, in persons under 65 years of age, 9 percent of whites, 18 percent of African Americans, and 26 percent of Hispanics were uninjured for health expenditures (Trevino and Moss, 1983). Among Hispanics, Mexican Americans, who comprise 60 percent of all Hispanics in the United States, have disproportionately higher rates of being uninsured than other Hispanic national origin groups. The Hispanic Health and Nutrition Examination Survey conducted from 1980-84 revealed that 35 of Mexican Americans of all age groups were uninsured, compared with 29 percent of Cuban Americans and 22 percent of mainland Puerto Ricans (Trevino et al., 1991). The 1990 Current Population Survey found that among Hispanics under 65 years of age, 42 percent of Mexican Americans, 23 percent of Puerto Ricans, and 22 percent of Cuban Americans were uninsured (Valdez et al., 1993). Trevino et al., have shown that uninsured minorities are often the poorest, least educated and most in need of health care of all minorities and have further shown that when poor minorities have health insurance, they do use the available health services (Trevino et al., 1996).

In 1994, the Commonwealth Fund sponsored the National Comparative Survey of Minority Health Care, a 25 minute telephone interview survey of 3,789 adults, 18 years of age or older. The sample included 1,114 whites, 1,048 African Americans, 1,001 Hispanics, and 632 Asian Americans (including 205 Chinese, 201 Korean, and 201 Vietnamese). Interviews were conducted in English, Spanish, Mandarin, Cantonese, Korean, and Vietnamese.

Findings from that survey revealed that overall, 31 percent of minority Americans, ages 18-64, and 14 percent of white Americans lack health insurance, with 41 percent of Korean American, 38 percent of Hispanic American, 26 percent of African American, and 23 percent of Asian American adults being uninsured. Although minority adults and white adults, ages 18-64 have comparable rates of employment (72 percent vs. 76 percent), minority adults are less likely than white adults to receive health insurance through their own employers (56 percent vs. 66 percent).

The Comparative Survey also found that minority adults are less likely to have a regular health care provider (66 percent), compared with 80 percent of white adults with Hispanics and Asians having the lowest rate of having a regular doctor (58 percent and 60 percent respectively). Twenty-nine percent of minority adults, compared with 16 percent of white adults report having little or no choice in where they get their health care. For those with a choice of doctor, minority adults were more likely to say that the doctor’s nationality, race, or ethnicity influenced their choice (12 percent) than were white adults (5 percent). Overall it was found that 25 percent of African Americans see African American providers; 21 percent of Hispanic American adults see Hispanic providers; and one-half of Asian Americans see Asian providers. Interestingly enough, a very recently published study also found that when potentially confounding variables were controlled, generalist physicians from underrepresented minority populations were more likely than their non-minority counterparts to care for medically underserved populations (Xu et al., 1997).

The survey found that in the past year, 15 percent of minority adults did not receive needed medical care compared with 13 percent of non-minorities. Paying too much for medical care was found to be a major problem for 40 percent of minority adults, compared with 26 percent of white adults. Waiting too long to seek care was a major problem for 27 percent of minority adults compared with 16 percent of white adults. Getting care from specialists was a major problem for 18 percent of minority adults compared with 8 percent of white adults. Minority individuals were twice as likely to experience difficulty getting a medical appointment (16 percent vs. 8 percent) and were twice as likely to be refused medical care (5 percent vs. 2 percent). One-fourth of minority adults in the United States do not speak English as their primary language and 21 percent of minority Americans indeed reported that language problems presented a problem for them in receiving medical care. Of those who did not speak English as a first language, 26 percent of Hispanics and 22 percent of Asians needed an interpreter when seeking health care.

Results of the Comparative Survey revealed that on average, white and black adults visit a doctor five times per year whereas Hispanics averaged four visits and Asians three visits per year. Of Americans who have visited a doctor in the past year, 26 percent of white adults did not receive preventive services such as blood pressure tests, pap smears or cholesterol screenings compared with 29 percent of minority adults. A few minority groups were significantly less likely to have received preventive services -- 47 percent of Vietnamese, 39 percent of Mexican Americans, and 38 percent of Puerto Ricans.

A sizable proportion of ethnic/racial minority group individuals who do consult a physician report negative experiences with the American health care system. Fully 15 percent of minority adults believe that they would have received better care if they had been members of a different race. Almost one in ten Americans felt that they were made to feel uncomfortable or treated badly when receiving health care in the prior year. For Cuban and Puerto Rican adults, the rates were higher (19 percent and 14 percent respectively). Among minority adults who reported being treated badly, 31 percent felt such treatment was due to their race and 48 percent felt it was due to their being poor. Less than half (46 percent) of minority individuals reported being very satisfied with their overall health services, compared with 60 percent of white adults. Overall, minority adults assign fewer "excellent" ratings to their doctors than white adults on providing good health care overall (53 vs. 58 percent), treating them with dignity and respect (64 vs. 71 percent), ensuring that they understand what they have been told (58 vs. 66 percent, listening to their health concerns and taking them seriously (56 vs. 63 percent), and being accessible (43 vs. 51 percent).

Lack of access to ambulatory health care on a timely basis or a poor experience with such care can lead to subsequent unnecessary hospitalizations and more expensive forms of health care. A recently published article revealed that rates of potentially avoidable hospitalizations were higher for persons living in middle and low income areas than for persons living in high income areas, and rates were higher for African Americans than for whites (Pappas et al., 1997). Their findings suggest that African Americans may experience increased barriers to ambulatory care at each median income group. The authors concluded that “this study reveals a substantial national problem with hospitalizations that may be prevented with timely, appropriate care” (Pappas et al, 1997, p. 815).

Explanatory Model

An explanatory model of health care access for minority populations has not been proposed in the literature. In the 1960’s, E. Fuller Torey posited that four factors had a potentially inhibiting influence on the use of mental health services by Mexican Americans. Noting that this population had the lowest use of such services among all populations despite a higher risk for mental disorder, he hypothesized that this decreased utilization was related to utilization barriers. Specifically, he hypothesized that language barriers, cultural barriers, geographic barriers, and class barriers resulted in decreased use of services. He reasoned that differences between therapist and patient with respect to their cultures, language, and social position were negatively associated with use of services as was geographic distance or lack of physical proximity of services. Trevino added the variable of financial barriers to service and tested the impact of the five hypothesized barriers on use of mental health services among Mexican Americans. His findings and those of others (Phillipus) revealed that when services were rendered in a multilingual manner by culturally diverse staff of varying social classes in a geographically and financially accessible fashion, expected utilization among minority populations can be achieved.

Publicly-Funded Health Insurance for the Poor

Medicaid is the publicly-funded health insurance program designed to care for the poor populations in the United States. It is funded through state and federal funds and managed at the state level. Each state designates a singe agency that is responsible for Medicaid program operations. The states determine eligibility of Medicaid applicants, determine provider qualifications, payment methods and levels as well as negotiate contracts with managed care plans and other providers. The state also processes and pays medical claims, communicates with beneficiaries and oversees quality of care in facilities funded by Medicaid.

For each state the federal medical assistance percentage (FMAP) is calculated using a formula that relates state per capita income to national per capita income, thus it is one measure of relative individual state poverty. The FMAP pays for medical services in Medicaid.

The state share is the difference between FMAP and the total costs for Medicaid. Medicaid programs, poverty lines and FMAP's vary considerably from state to state. The percentage of Medicaid costs borne by the federal government varies from 50 percent in more affluent states to 79 percent in the poorest states and averages 57 percent nationwide (Bonnyman, 1996).

A state's Medicaid plan must be in effect throughout the entire state. Services covered in one state location cannot be different than those covered in another part of the state. Medicaid recipients must maintain freedom of choice in selecting a provider. Services must be comparable. This means that the amount, duration, and scope of services must be equal among all eligible groups. The U.S. Secretary of Health and Human Services may grant a waiver of these requirements under two broad categories; research and demonstration waivers (1115 waivers) and freedom of choice waivers along with home and community based service waivers (1915 waivers).

Medicaid operates as a vendor payment program, with payments made directly to providers by states. Payment levels are subject to conditions that all state Medicaid plans and agencies must satisfy. Payments must be sufficient to enlist enough providers to participate in the plan and ensure comparable services statewide. Participating providers must accept the Medicaid reimbursement as payment in full and payments to providers must be consistent with efficiency, economy and quality of care standards. States must also maintain payment records, provide a description of payment methodologies and policies and notify providers of changes.

To be eligible for federal funds, states are required to provide Medicaid coverage for most individuals who receive federally assisted income maintenance payments as well as for related groups not receiving cash payments. Eligibility is usually calculated on a monthly basis and some services may be provided for groups while they are deemed pre-eligible for services.

Mandatory coverage is given to families who receive cash payments under the Aid to Families with Dependent Children (AFDC) or the AFDC unemployed parent provisions. Additionally, aged, blind and disabled individuals receiving assistance under the federal Supplemental Security Income (SSI) program, all have mandated coverage. Pregnant women and/or postpartum women and children under 6 years of age whose family incomes do not exceed 133 percent of the federal poverty line also receive coverage. States are also required to extend Medicaid eligibility until 19 years of age to all children born after September 30, 1983, in families at or below the federal poverty level. This coverage is being phased in so that by the year 2002, all poor children under 19 years of age will be covered.

All states have the option to extend eligibility to certain groups. Optional eligibility groups may include infants up to 1 year of age and pregnant women not covered under the mandatory rules whose family incomes are more than 133 percent but not more than 185 percent of the federal poverty level. Additionally, certain aged or disabled individuals, children, caretaker relatives, institutionalized individuals, pregnant women and tuberculosis infected persons who are slightly above the federal poverty level, would meet SSI or whose eligibility for Medicaid is in the presumptive stage of eligibility may receive coverage. Presumptive eligibility is primarily assumed for pregnancy related services. Some states also operate medically needy programs.

Medicaid functions as a payer of last resort. Beneficiaries must first exhaust other third party insurance coverage, including commercial insurance and Medicare coverage.

Managed Care

Managed health care organizations integrate the delivery and financing of health care for their members. This integration changes the historical supply side (provider) incentives. Thus, the change in incentives forces the provider to bear part of the financial risk, and the organization has a strong incentive to reduce excessive care and inefficiencies as well as improve quality and cut costs (Folland, Goodman, and Stano, 1993).

Studies have shown that managed care may be quicker to develop utilization review procedures and adapt new technology more efficiently, and may reduce quantity and intensity of care, substitute lower cost care for higher cost care, have economies in purchasing and administrative costs related to insurance marketing, medical underwriting, agent's commissions, premium collection, claims processing, insurer profit, quality assurance programs and risk management, as well as encourage cost effective preventive care Folland, Goodman, and Stano, 1993).

The impact that managed care has had on private (indemnity) health insurance in the United States is exemplified by the fact that in 1988 indemnity insurance accounted for 72.6 percent of the private health insurance market, by 1993 it had been reduced to only 33.3 percent. Most managed plans have been sponsored by employers, who have been seeking alternatives to fee for service health care in order to control health care costs. In the public sector, the number of Medicaid and Medicare managed care programs have more than tripled between 1983 and 1991 (Weiss, 1995).

Managed health care organizations take a variety of forms including health maintenance organizations (HMO's), preferred provider organizations (PPO's) and point of service plans.

HMO's offer prepaid, comprehensive health coverage for both hospital and physician services. An HMO contracts with health care providers and members are required to use participating providers for health services. Members are enrolled for a specified period of time. HMO models include staff, group practice, network, and IPA's.

Staff models deliver health services through a physician group that is controlled by the HMO unit and most physicians are salaried employees who deal exclusively with the HMO. Group practice models contract with a multi-specialty medical group to provide care for HMO members and members are required to receive medical care from a physician within the group unless a referral is made outside the network. Network models contract with two or more independent group practices to provide health services. This type may include a few solo practices, but is primarily organized around groups. Independent Practice Associations (IPA's) are models which contract with a physician organization, which in turn, contracts with individual physicians. The IPA physicians practice in their own offices and continue to see fee-for-service patients. The HMO reimburses the IPA on a capitated basis; however, the IPA usually reimburses the physicians on a fee for service basis.

A PPO is a health care arrangement between purchasers of care (e.g. employers, insurance companies) and providers that provide benefits at a reasonable cost by providing members incentives (such as lower deductibles and copays) to use providers within the network.

A Point of Service plan (POS) is also known as an open-ended HMO. This type of model encourages but does not require members to choose a primary care physician. Plan members may visit non-network providers at their discretion. Members electing not to use the primary care physician must pay higher deductibles than those using network physicians.

HMO's enrolled 7.7 million new members between July 1994 and July 1995, and total HMO enrollment was 54 million as of July 1995 (Currents, 1996).

Enrollment in PPO's increased from 12.2 million in 1987 to 76.6 million in 1993 (Weiss, 1995)

Even as traditional HMO's continue to add patients, new forms of managed care are constantly evolving. HMO's that offer a point of service option represent the largest and fastest growing segment of the market, and among all HMO's those contracting with IPA's are the most popular (Weiss, 1995).

Managed care organizations negotiate reimbursement packages with delivery systems and providers in several ways, with varying degrees of risk. Risk is defined as the chance or possibility of loss. for example, physicians may be held at risk if hospitalized rates exceed agreed upon thresholds. The sharing of risk is often employed as a utilization control method within the HMO setting. Risk is also defined in insurance terms as the possibility of loss associated with a given population.

One of the most popular and most restrictive reimbursement mechanisms used by managed care organizations is captivation. Captivation is a reimbursement mechanism by which a negotiated fixed monthly fee is paid to the health care provider per member per month. The provider carries all the risks involved, including ancillary use, length of stay and pricing. Under capitation, the health care provider must carefully manage the patient's care within the negotiated capitation contract. The provider must utilize financial planning to insure that the costs of treating a patient for a certain diagnosis lie within the capitation contract.

Medicaid and Managed Care

There exists bipartisan support for the concept that states should have the flexibility to enroll Medicaid beneficiaries in managed care plans (Iglehart, 1995). This support stems from the belief that managed care is a way to stem the rapid growth of Medicaid expenditures and state funds and as a way to expand coverage to more uninsured persons with low incomes.

The health care system in the United States is thus moving from fee-for-service to capitation, where individual providers are merging into integrated delivery systems and managed care systems are vying for business in a newly created price sensitive market.

Historically, for profit corporations shunned the Medicaid market, leaving the job to nonprofit HMO's organized by charity hospitals, community clinics, and physicians working in poor neighborhoods. Now with state Medicaid programs leaping into managed care, offering huge and potentially lucrative contracts, commercial plans are actively seeking this market (American Medical News, April 1996).

Medicaid is now attractive to managed care companies because it delivers a large ready made pool of enrollees that otherwise would take years of costly and uncertain marketing efforts to develop. With the instant market share that a Medicaid contract can provide, such companies enjoy important advantages in the scramble to build provider networks and compete for the more lucrative business of private purchasers (Bonnyman, 1996).

Medicaid Managed Care Programs

As stated earlier, almost every state has implemented some sort of Medicaid managed care program. State governments are counting on managed care to contain costs and improve access to care. Following are a few examples of programs across the nation:

The state of Tennessee has been a pioneer in the Medicaid managed care movement. Caught between a major loss of federal Medicaid funds and legislators' fears of enacting new taxes, Governor Ned McWerter declared in early 1993 that he would make Tennessee the first state in the nation to withdraw from Medicaid. Within months, Tennessee had obtained a federal waiver under section 1115 of the Social Security act and had launched a managed care program that would affect the state's entire health care delivery system.

At the end of it's first year the program, known as TennCare had expanded coverage to 300,000 previously uninsured Tennesseans, while bring Medicaid spending under control. More fundamentally, TennCare transformed the provisions of health care to Medicaid beneficiaries from a seller's market into a buyer's market.

For an initial average rate of $101 per member per month, TennCare paid 12 managed care organizations to deliver care to the program's beneficiaries. Borrowing a contract enforcement tool common to commercial markets but novel in Medicaid, TennCare withholds from each organization 10 percent of its monthly capitation payment, contingent upon the plan's compliance with performance standards. In every region, beneficiaries have a choice of at least 2 managed care plans. The managed care organizations are responsible for all covered services except long-term care, which continues to be reimbursed directly on a fee-for-service basis (Bonnyman, 1996).

Although TennCare has had numerous start-up problems and some criticisms, it remains a model for the rest of the nation in developing and implementing Medicaid HMO's. By 1994, TennCare had achieved an enrollment of 1.2 million, including a net FTE of 300,000 previously unenrolled Tennesseans, half of whom were poor. A telephone survey conducted by the University of Tennessee indicated that between private insurance and TennCare, 94.6 percent of the state's residents enjoyed some form of health care coverage -- closer than any state previously come to assuring universal coverage (Bonnyman, 1996).

The state of New York has a long history of providing access to poor people through public programs. In June 1991, the legislature enacted a sweeping managed care initiative, declaring that 50 percent of the state's 2.5 million Medicaid clients would be enrolled in managed care before the end of the decade. With only 75,000 clients in managed care, the initiative promised to revolutionize the state's Medicaid program (Sparer, 1996).

Currently 415,000 or one-fourth of New York City's Medicaid beneficiaries are enrolled in Medicaid managed care programs, and all 57 of the state's counties have exceeded their enrollment targets (Sparer, 1996). Initially, the program cost the state money because they set capitation rates assuming a certain average risk per patient. Those who signed up for managed averaged below that rate.

There is some evidence that the program in New York has achieved some of its goals. In July 1996, an evaluation of the program found that Medicaid managed care enrollees in New York City reported better access to care and higher levels of satisfaction compared with conventional Medicaid beneficiaries (Sisk, et al. 1996).

By far the most controversial Medicaid managed care plan has been the effort by the state of Oregon to revamp their program into the Oregon Health Plan (OHP). Although Medicaid reforms were not the sole purpose of the OHP, many criticisms of the plan have focused on the benefit package created for Medicaid recipients. The goal of the OHP is to ensure access to health insurance for all Oregonians. Beginning in 1989, a trio of bills enacted by the legislature has received great publicity and worldwide attention due to the concept of rationing. The bills were designed to rationalize the concept of rationing by defining what services would be covered, rather than making choices about who would be covered.

This change was facilitated by insurance reforms in the area of small market, employer mandates, high risk pooling and Medicaid. The most controversial of the reforms is the assignment of priority ranking to health care services. This was accomplished in the original Oregon proposal by using four levels of human judgment: community values assessed in town meetings; ratings of the desirability of health states; medical judgment of treated efficacy and subjective reordering of the list by Oregon Health and Human Services (Bussman).

In August 1992, the U.S. Department of Health and Human Services rejected the original waiver application due to the use of ratings of the desirability of health states as one of the judgment levels. The state resubmitted the plan which was then approved in March 1993. The Oregon Health Plan addresses the needs of 450,000 Oregonians presently without health insurance, among them 120,000 living in poverty who are not now Medicaid eligible. This was accomplished by eliminating the use of categorical eligibility. Eligibility for Medicaid coverage was expanded to individuals and families with incomes at 100 percent of the federal poverty level. Managed care organizations provide care at a reasonable cost, and to help expand access within the limitations of the state budget, certain services, determined to be of limited value or effectiveness were not covered for payment (Bussman).

The Oregon Health Plan introduced a rational although controversial plan for expanding services to the entire population of the state, while acknowledging the limitations of funding resources.

While health care reform proposals continue to be debated at the national level, it is entirely likely that any reforms to the system will be enacted at the state level. States continue to propose and implement reform measures to address Medicaid, universal coverage and access, health insurance and cost containment.

The Health Care Financing Administration estimates that about 80 percent of Medicaid managed health care plans have saved money, typically 5-15 percent over fee-for-service for the same populations. The bulk of the saving have come from lower use of emergency services, because recipients have gotten their primary care in a physician's office rather than the more expensive emergency room setting. Money is thereby freed to effectively increase compensation for physicians through capitated contracts (American Medical News, October 1995).

Medicaid managed care has increased primary care access, raised per-encounter rates for the physicians, and lowered overall costs to the states. Medicaid patients have been brought into the medical mainstream, and the quality and oversight of services have been improved (American Medical News, October 1995).

Ethnic/Racial Minorities, Managed Care and Medicaid

While it is clear that Medicaid, the nation's major public program designed to increase access to health care for poor persons, is increasingly moving toward managed care it is less clear how ethnic/racial minorities who comprise a major segment of the recipients of this program will be impacted by this trend. The limited research that has been conducted on managed care and Medicaid to date has found a positive impact on cost reduction along with better access to care and higher levels of satisfaction when compared with conventional Medicaid beneficiaries (Bonnyman, 1996; Sparer, 1996; and Sisk, et al., 1996).

A significant question that has not been as well addressed is whether the increasing enrollment of Medicaid recipients in managed care has resulted in increased access to care, acceptability of care and quality of care for ethnic/racial minority populations.

Comparative Analysis of Problems, Strategies, and Approaches

Given that this was the first conference to bring together health providers, administrators, and researchers from both the United States and the United Kingdom to specifically address the issues related to the quality and quantity of health care received by minority populations, there was much enthusiasm, sharing and interest in collaboration exhibited by the conference participants. All in attendance agreed that this conference was invaluable, overdue, and needed to be followed by other such consultative opportunities.

Conference deliberations focused on the similarities and differences between the US and UK health care systems in terms of providing accessible and acceptable care for minority populations. Clearly there are differences in the size, origin, culture, language, and experience of the minority populations.

One conference participant remarked that the overarching difference in access to health care between the US and UK health care systems in terms of providing accessible and acceptable care for minority populations. Clearly there are differences in the size, origin, culture, language, and experience of the minority populations of these two countries as there are differences in the health care delivery systems. Despite these differences, a great number of similarities were also noted. All present believed that through the exploration of these similarities and differences we could achieve useful models to achieve a more favorable health status for all minority populations.

One conference participant remarked that the overarching difference in access to health care between the US and the UK was that in the UK the problem was related to lengthy waiting times while in the US the problem revolved around the very large and growing population without health insurance coverage. However, even though the UK may have fewer financial access barriers for their minority populations, both countries need to mount interventions to make health services more acceptable and relevant for all of their populations.

Participants noted that both countries have experienced a slow policy formulation process for addressing their minority health issues. In the UK it was noted, Black and ethnic minorities have resided in the country since the 1950s yet the relevant National Health Service policy originated in the 1980s. In the US, relevant policy followed the introduction of ethnic and racial minorities by hundreds of years.

It was unanimously observed that both countries needed to address the significant problems associated with not having a culturally representative health professions workforce. It was noted that achieving a more representative health workforce could make health services more acceptable and relevant for ethnic and racial minorities and could also help ameliorate the underlying socioeconomic basis of minority health concerns. A high priority for both countries is to significantly increase the participation of minorities in health policy-making bodies and to provide appropriate training for all of their health policy makers.

Another element of representativeness revolves around the need to increase the numbers of minority populations involved in clinical trails and other health investigations so that we may have the most timely and scientifically rigorous treatment protocols for all populations groups. It was observed that in both countries, not all minorities had negative health outcomes. Indeed it is through the exploration of divergent health outcomes both positive and negative that we can better understand the underlying processes. It was reported that in the UK they were adopting minimum health data sets to help evaluate how minorities use health services. The two countries share a need for a national research strategy and a need to train and involve more minority health researchers. Several present also felt that we needed to more effectively link public health research with social policy research. Clearly, both countries need to accurately forecast minority populations so that we do not plan inappropriate services. It was observed the health trusts in the UK have a greater opportunity to influence health professions schools when they start negotiating their contracts with schools by comparing how their graduating classes compare with the future needs of the populations to be served.

Accessible, acceptable, and appropriate health care is only possible if we properly engage the minority community. The relatively poor health of minority populations in both countries is largely attributable to the poor socioeconomic status of those groups. Both countries need to expand their emphasis on involving the community in the design of their health services. It is imperative that both engage in coalition-building so as to develop partnerships with the community. Both countries need to target their outreach to the minority community.

The UK and the US also share the need to mainstream the minority agenda to assure that it not serve as an afterthought. Toward this end, conference participants noted the need for a focal point within their government for minority health concerns. While this may be organized differently between the two countries (for example, the Office of Minority Health in the US and the Department of Health office of the Advisor on Ethnic Minority Health in the UK), it is essential that the corresponding office have access to and the confidence of the highest national health policy maker.

Lastly, it was the consensus of the conference that the United States and the United Kingdom need to continue to support and consult with each other so as to develop more effective health policy for all.

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The Monitoring of Racial/Ethnic Status in the United States:

Data Quality Issues

by

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Race has not been measured in a consistent manner over time in the United States. Race has been measured in the decennial census since its inception but the Census Bureau has routinely changed its racial categories over the last two centuries, with no racial classification scheme having been used in more than two Censuses (Martin, DeMaio, & Campinelli, 1990). The Federal government's Office of Management and Budget (OMB) current guidelines for measuring race and ethnicity in the U.S. recognizes four racial groups (white, black, Asian or Pacific Islander [API], and American Indian or Alaskan Native) and one ethnic category (Hispanic) in the United States. This directive has been in effect since 1977. Recently, the OMB has proposed new guidelines that must be implemented in all federal statistical programs by the year 2003. These new guidelines recognize five racial groups (white, black or African American, Asian, Native Hawaiian or other Pacific Islander, and American Indian or Alaska Native) and one ethnic category (Hispanic or Latino). In addition, the new guidelines will allow persons of mixed racial ancestry to list themselves in as many racial categories as apply. Standardized tabulation procedures for counting persons who identify with more than one race have not yet been developed.

From the very beginning, racial categories in the United States reflected a hierarchy of racial preference that was driven by a racist ideology. Three of the four currently recognized racial categories were in the very first census in 1790 and they were not regarded as equal. In compliance with Article One of the U.S. Constitution, this census enumerated whites, blacks as three-fifths of a person and only those Indians who paid taxes. The Thirteenth Amendment abandoned the Three-Fifths Rule, but Indians continued to be divided into the categories of "civilized Indians" and "Indians not taxed" until 1924 when all American Indians were granted U.S. citizenship by Congress (Anderson & Feinberg, 1995).

Race has been a fundamental organizing principle of U.S. society (Omi & Winant, 1986). Historically, attitudes and beliefs about racial groups have been translated into policies and societal arrangements that limited the opportunities and life chances of stigmatized groups. Minority populations' disproportionate representation at the lower levels of socioeconomic status (SES) reflects the successful implementation of social processes that were designed to relegate groups with undesirable physical characteristics such as skin color to positions and roles consistent with the dominant society's evaluation of them. Not surprisingly, race has emerged as an important determinant of variations in health.

This paper provides a brief overview of the measurement of racial/ethnic status in selected surveys and major data collections of the U.S. Department of Health and Human Services. It will especially attend to current measurement and methodological issues in the study of racial differences in health in the United States and provide an overview of the current problems with racial data and the critical role of socioeconomic status (SES) for understanding racial/ethnic disparities.

RACIAL/ETHNIC MEASUREMENT IN THE U.S. DATA SYSTEMS

This section will provide a brief overview, with representative examples, of major population-based surveys, record-based surveys and the vital statistics system in the U.S. Table 1 provides basic descriptive information for each data source and the availability of racial/ethnic and SES data is noted.

Population-Based Surveys

National Health Interview Survey

The National Health Interview Survey (NHIS) is a principal source of information on the health of the civilian noninstitutionalized population. The survey, conducted annually since 1957, collects information from approximately 50,000 households and 110,000 people on health status, access to care and insurance, health services utilization, health behaviors and other topics. The survey consists of a set of core data items that are repeated each year and a set of supplements that can change each year to address current health topics.

Core data are collected on the incidence of acute conditions, episodes of persons injured, prevalence of chronic conditions and impairments, restriction in activity due to impairment or health problems, respondent-assessed health status, utilization of health care services involving physician care and short-stay hospitalization, and demographic and socioeconomic characteristics. Data on the four OMB racial categories and Hispanic origin are collected. In addition, sub-group identifiers are collected for ten API populations and four population groups within the Hispanic category.

National Survey of Family Growth

For more than 20 years, NCHS has been conducting household interviews of women 15-44 years of age to monitor changes in childbearing practices and to measure reproductive health. The 1973 and 1976 surveys included only never-married women, and the 1982 and 1988 surveys represented all women, 15-44 years of age. In 1990, the 1988 participants were reinterviewed by telephone.

The survey provides data on contraception, infertility, use of family planning and infertility services, sexual activity, family formation, family size and related aspects of maternal and child health such as adoption. Racial/ethic identifiers are included for the five OMB categories in this survey.

Record-Based Surveys

National Health Care Survey

To meet the health statistics needs of the future, a number of the Center's record-based surveys were merged and expanded into one integrated survey of health care providers called the National Health Care Survey (NHCS). In addition to data on traditional health care settings such as hospitals, the NHCS now provides data on alternative health care settings such as ambulatory surgical centers, hospital outpatient departments, emergency rooms, hospices, and home health agencies. Thus the survey is a source of a wide range of data on the health care field and a significant resource for monitoring health care use, the impact of medical technology, and the quality of care provided to a changing American population.

NHCS was built upon the following current NCHS surveys: the *National Hospital Discharge Survey*, the *National Ambulatory Medical Care Survey*, and the *National Nursing Home Survey*. These were complimented by three new surveys: the *National Survey of Ambulatory Surgery*, the *National Hospital Ambulatory Medical Care Survey*, and the *National Home and Hospice Care Survey*. Data are included for the five OMB categories in each of these surveys.

National Hospital Discharge Survey (NHDS). The National Hospital Discharge Survey is the principal source of information on inpatient utilization of hospitals. Conducted annually since 1965, the survey provides data on the use of non-Federal short-stay hospitals, on their size, location and ownership as well as data on diagnoses, surgical procedures, length of stay, expected source of payment and patient characteristics. Data from the NHDS are useful for tracking specific diseases, the introduction of new technologies, and the impact of changes in financing systems. The survey is currently based on data abstracted from 274,000 records from 525 hospitals.

National Ambulatory Medical Care Survey. The National Ambulatory Medical Care Survey provides data on visits to physicians, including information on patient characteristics, diagnostic procedures, patient management, and planned future treatment. The survey was conducted annually from 1974-81, in 1985, and annually since 1989. Data are collected using encounter forms from approximately 3,000 physicians from a sample of 40,000 visits. Data collection from the physician, rather than from the patient, provides an analytic base that expands information on ambulatory care collected through other NCHS surveys.

National Nursing Home Survey. The National Nursing Home Survey provides information on nursing homes from two perspectives--that of the provider of services and that of the recipient. Data about the facilities include characteristics such as size, ownership, Medicare and/or Medicaid certification, occupancy rate, days of care provided, and expenses. For recipients, data are obtained on demographic characteristics, health status, and services received. Conducted periodically since 1963 and most recently in 1995, the survey is based on self-administered questionnaires and interviews with administrators and staff in a sample of about 1,500 facilities.

National Survey of Ambulatory Surgery. Although data have been available for three decades for surgery on inpatients, advances in medical technology permit a wide variety of surgical and diagnostic treatments outside the inpatient setting. The National Survey of Ambulatory Surgery provides detailed data on the use of free-standing and hospital-based ambulatory surgery centers in the United States. Data collection began in 1994 and data are available on patient characteristics including age and sex; administrative information including patient disposition, expected sources of payment, and region of the country where surgery was performed; and medical information including diagnoses, surgical operations, and diagnostic procedures performed.

National Hospital Ambulatory Medical Care Survey. The National Hospital Ambulatory Medical Care Survey produces statistics representing the experience of the U.S. population in hospital emergency departments and outpatient departments. Specifically, the survey provides information on the demographic characteristics of patients, expected source of payment, patients' complaints, physicians' diagnoses, diagnostic and/or screening services, procedures, medication therapy, disposition, types of health care professionals seen, and causes of injury where applicable. Data collection began in 1992 and has continued annually. Data are abstracted from 70,000 medical records of visits to 440 hospitals.

National Home and Hospice Care Survey (NHHCS). The

NHHCS provides data on home health agencies and hospices and their current patients and discharges. Conducted annually since 1992, the survey was established in response to the rapid growth in the number of home health agencies and hospices throughout the United States and the need to assess the availability and utilization of these services. Personal interviews with administrators and staff provide information from approximately 1,500 sample agencies. Data are collected on referral and length of service, diagnoses, number of visits, patient charges, health status, reason for discharge, and types of services provided.

National Vital Statistics System

The National Vital Statistics System is responsible for the Nation's official vital statistics. These vital statistics are provided through state-operated registration systems and are based on vital records filed in state vital statistics offices. The registration of vital events--births, deaths, marriages, divorces, and fetal deaths--is a state function. NCHS cooperates with the states to develop and recommend standard forms for data collection and model procedures to ensure uniform registration of the events. The Center shares the costs incurred by the states in providing vital statistics data for national use.

Detailed annual data on births, deaths (including infant deaths), and fetal deaths are available for the United States and for states, counties, and other local areas. Monthly provisional data are available for the United States and each state. For births and deaths, data for the five OMB categories, including subgroups of the API and Hispanic population are collected.

Linked Files of Live Birth and Infant Death Records. These research files allow researchers to explore the complex relationships between infant death and risk factors present at birth. The linked files include information from the birth certificate such as birth weight, mother's age, and prenatal care, linked to information from the death certificate for the same infant, such as cause of death and age at death. The files are birth-cohort-linked files. They are based on deaths under 1 year of age of all infants born in a calendar year. Each file contains approximately 40,000 linked records. The first annual national linked file was for the 1983 cohort under a pilot project. Beginning with the birth cohort of 1987, linked files are part of the national vital statistics system.

National Death Index. Working with state offices, NCHS established the National Death Index (NDI) as a resource to aid epidemiologists and other health and medical investigators with their mortality ascertainment activities.

The NDI is a central computerized index of death record information compiled from magnetic tapes submitted by state vital statistics offices. Beginning with 1979 deaths, death records are added to the NDI file annually, approximately 10 months after the end of a particular calendar year. The index assists investigators in determining whether persons in their studies have died and, if so, provides the names of the states in which those deaths occurred, the dates of death, and the corresponding death certificate numbers. Investigators can then arrange with the appropriate state offices to obtain copies of death certificates or specific statistical information as cause of death. The index is available to investigators solely for statistical purposes in medical and health research. It is not accessible to organizations or the general public for legal, administrative, or genealogy purposes.

THE QUALITY OF RACIAL DATA

Race is routinely used in an uncritical manner with little attention given to the underlying problems of measurement that exist for the current racial categories (Hahn, 1992; Williams, 1994; LaVeist, 1994; Jones, LaVeist, & Lillie-Blanton, 1991). These problems importantly affect the quality of U.S. health data.

Measurement Error: Observer Bias

The numerator for the officially reported death rates in the U.S. comes from death certificates. There are reliability problems with the assessment of race that suggest that there is an acute problem of undercounting racial\ethnic status for Native Americans, APIs and Hispanics. A major source of this undercount is the discrepancy between interviewer observed race and respondent self-report. Between 1957 and 1977 race was determined by interviewer observation in the Health Interview Survey. In 1978, the year in which the measurement of race was changed in that survey, racial information was collected both by interviewer observation and respondent self-report. Analyses of the discrepancy between these two measurement strategies revealed that 6 percent of persons who reported themselves as black, 29 percent of self-identified Asian Pacific Islanders, 62 percent of self-identified American Indians and 80 percent of persons who self-identified with an "other" category (70 percent of whom were Hispanic) were classified by the interviewer as white (Massey, 1980).

Respondent self-report is not an option on the death certificate, but it appears that officials who complete these forms determine racial/ethnic status based on their own judgment instead of obtaining the race of the deceased from the next of kin. A national survey of vital registrars found that they believed that only 63 percent of medical examiners, 50 percent of coroners and 47 percent of funeral home directors use the recommended method on relying on family members for racial information (Scott & Suagee, 1992). They also indicated that funeral home directors view requesting racial information as imposing a burden on the family. Misclassification of Asian Pacific Islanders or American Indians as white would suppress the death rates for these groups. Some evidence suggests that this does, in fact, occur. Sorlie et al. (1993) compared race ascertained in a personal interview with a knowledgeable adult household member in 12 Current Population Surveys, with race recorded on the death certificate as found in the National Death Index (NDI) for the years 1979-1985. This study found high agreement for whites (99.2 percent) and blacks (98.2 percent) of self-reported racial status with racial status from death certificates. However, 26 percent of self-identified American Indians, 18 percent of Asian Pacific Islanders, and ten percent of Hispanics were classified into another racial category on the death certificate. Most of these persons were classified as white.

Studies of the Indian population provide further documentation of this problem. A study in Oklahoma found that 28 percent of Indian infants were misclassified as another race on the death certificate (Kennedy & Deapen, 1991). After adjusting for this misclassification the infant mortality rate doubled from the currently reported 5.8 per 1,000 to 10.4 per 1,000. Similarly, another study found that only 60 percent of cancer patients registered with the Indian Health Service as American Indians were identified as Indians in the cancer surveillance registry (Frost, Taylor, & Fries, 1992). This led to an underestimation of cancer incidence rates for Native Americans.

Reliability: Change in Racial Identity

Inconsistencies in reporting race/ethnicity over time is another problem. A study of a large national population found that one-third of the United States population reported a different racial or ethnic status one year after their initial interview (Johnson, 1974). For example, six percent of Negroes, 12 percent of Mexicans, 20 percent of Polish, 34 percent of Germans, and 45 percent of persons who said they were English, Scottish or Welch, reported a different racial or ethnic category in 1972, compared to 1971.

The most dramatic evidence of change in self-identification comes from analyses of trends in the Indian population over time. Between 1960 and 1990 there was a sixfold increase in the American Indian population (Eschbach, 1995). This dramatic growth of the population cannot be explained either by biological growth or international migration. It appears to reflect a change in self-definition, with more adults of mixed ancestry identifying themselves as American Indian. This shift in self-identification into the American Indian population is more common at younger ages and does not vary by gender (Passel & Berman, 1986; Harris, 1994).

The degree of identification as Indian may not be very strong for many of these "new Indians" (Passel & Berman, 1986; Eschbach, 1995; Harris, 1994). Most persons reporting American Indian ancestry did not report American Indian race, with 77 percent of persons who reported American Indian ancestry in the 1980 Census, indicating that their race was white (Passel & Berman, 1986). American Indian identification for this group may be optional and contextual, depending on the form of the race question, economic incentives for being American Indian in some states, reduced discrimination against American Indians, an increased willingness to self-identify as American Indians, and the increased use of self-enumeration in the Census (Passel & Berman, 1986). Given current rates of intermarriage of Indians with persons of other races there is likely to be continued rapid growth in the pool of persons who will be of some Indian ancestry, but for whom this ethnic identification may not be consequential. Fifty-nine percent of all married American Indians in 1990 were married to non-Indians (Eschbach, 1995).

Definition of Racial Groups

The discussion of establishing the racial status of American Indians raises the more general problem of establishing the race of an individual whose parents are of different races. Birth certificates in the United States do not list the race of the child but they include the race of both parents. Prior to 1989 the National Center for Health Statistics used a complicated algorithm to determine the race of children whose parents belonged to different races. According to this scheme, if the father was white, the child would be given the race of the mother; but if the father was non-white the child would be assigned the race of the father. If one parent was Hawaiian then the child was Hawaiian. Thus, unlike the assignment of race for all other racial groups, a child would be white only if both parents were white. Since 1989, the National Center for Health Statistics no longer reports vital statistics by the race of the child, but reports all birth data by the race of the mother. However, the Indian Health Service continues to consider a child as Indian if either the mother or father is American Indian and there is considerable discrepancy in the publication of infant mortality rates by race of child or by race of mother. For example, in 1989 there were 39,478 American Indian births as calculated by race of mother but 49,267, as calculated by race of the child (Scott & Suagee, 1992).

The question of how to classify persons whose parents are of different races continues to be a hotly debated policy issue in the United States, with some groups pushing for changes in the OMB's racial standards that would include a new category of multiracial status for all persons whose parents come from more than one of the four official racial groups. The current trends of interracial marriage suggests that this question will apply to an ever increasing proportion of the population. Twenty-five percent to 44 percent of Hispanics marry non-Hispanics and from 25 percent to 50 percent of API subgroups marry persons of other races (Rumbaut, 1994). Rates of black-white intermarriage are considerably lower but they increased from two percent in 1970 to six percent in 1990. The states of Ohio and Illinois now require that the multi-racial category must be added to school forms while Georgia and Michigan requires it on written forms used by state agencies.

Researchers have not given systematic attention to the extent to which the health profile of persons of mixed racial parentage differs from that of the standard racial categories. One recent study suggests that this association may be complex and that any attempt to assess multiracial status should include assessment of the race of both parents. Collins and David (1993) found that infants born to black mothers and white fathers had a higher rate of low birthweight than those born to white mothers and black fathers.

Definitional problems are not limited to multiracial status. The classification of the entire population into racial groups is neither simple nor straightforward. These problems are readily evident for the American Indian population. Indian tribes do not agree on who is American Indian with some using a strict definition based on blood quantum level, while others require identification with Indian culture or participation in tribal affairs. In the United States, a national debate continues over how race should be conceptualized and measured (Evinger, 1995). There is disagreement over the optimal terminology to be used for particular racial groups, whether new ethnic categories should be added (for persons from the Middle East or the Cape Verde islands), and whether Hispanic should be a racial or an ethnic category.

The categories of race and ethnicity are often assessed differently by various health agencies. The Centers for Disease Control and Prevention uses one question to capture OMB's five required racial categories in its national notifiable diseases surveillance system. However, many health surveys and other Federal data collection systems use one question to assess race and a separate one to assess Hispanic origin. Similarly, although the standard birth and death certificates were revised in 1989 to include Hispanic identifiers, the wording of the question varies from state to state and the data on Hispanic ethnicity is not completely reported in all states (U.S. Public Health Task Force, 1992).

These differences are important because the size of a racial/ethnic population depends on the wording of the question. In the 1980 census 26.5 million Americans self-identified as "black or Negro," but only 21 million indicated that they were of Afro-American ancestry (Hahn, 1992). Similarly, there were 1.5 million American Indians based on answers to the race question in the 1980 census, but 6.8 million based on responses to the ethnic ancestry question (Snipp, 1989).

Respondents also vary in their preferred term for self-identification. A recent national study of over 60,000 adults found that members of racial groups are divided over preferred terminology (Tucker et al., 1996). Fifty-eight percent of Hispanics preferred "Hispanic" (12% prefer "Latino"), 62% of whites preferred "white" (17% prefer "caucasian"), 44% of blacks preferred "black" (28% prefer "African American"), and 50% of American Indians prefer the term "American Indian" (37% prefer "Native American"). In an effort to respect individual dignity, researchers should use the most preferred terms for each group interchangeably (e.g., black or African American, Hispanic or Latino).

The implementation of the OMB's Directive 15 frequently violates an important principle of classification, namely, the creation of a set of exhaustive and mutually exclusive groups. Valid statistical tests are based on the assumption that the various categories in the classification system are independent samples. This assumption is not met for much of the routine reporting of health data in the U.S. (that provides information for non-Hispanic whites, non-Hispanic blacks, Hispanics and APIs). There are black Hispanics, Asian Hispanics, American Indian Hispanics and white Hispanics. Del Pinal (1992) has shown that the overlap of race with the Hispanic category affects the patterns of racial/ethnic differences not only for Hispanics but for the other racial categories as well.

Census Undercount

Another problem affecting the quality of health data in the United States is Census undercount. Census data are used to calculate the denominators for mortality rates. They are also used to construct sampling frames and adjust for nonresponse in population-based epidemiologic studies. The use of a denominator that is undercounted inflates the obtained rate in exact proportion to the undercount in the denominator. Thus, all rates of health events that use census data as denominators are overestimated by the same percentage as the population undercount in the denominator.

For the last several decades the United States Census Bureau has been evaluating the extent of undercount by means of demographic analysis. This strategy produces estimates of the population based on administrative data and demographic trends. Consistently, these analyses reveal that, while the overall undercount for the United States population is small, it is larger for blacks than for whites, and despite a steady decline in the undercount rate for blacks between 1940 and 1980, there was an upward trend between 1980 and 1990 (Robinson, Bashir, Prithwis, & Woodrow, 1993). The undercount rate for the overall population does not importantly distort health data, but the undercount rate varies considerably for some demographic subgroups.

In 1990, the overall undercount was 1.8 percent for the U.S. population and 5.7 percent for the black population. However, census undercount was dramatically higher for black males (8.5 percent) than for black females (3 percent), and varied by age such that there was a net census undercount of 11 percent to 13 percent for all of the 10-year age categories of black males between the ages of 25-64 (NCHS, 1994). Demographic analysis estimates are available only at the national level and it is likely that the omission of black males from households (the major cause of the undercount of blacks) varies by geographic area. Estimates of undercount based on demographic analyses are only as good as the underlying assumptions and concerns have been raised about the extent to which the demographic analysis methods are becoming less reliable over time (Notes and Comments, 1994).

The evaluation of the undercount problem by the Census Bureau has focused heavily on the black and white population. However, there is reason to believe that census undercount may also be a significant problem for some of the other racial populations. For the 1990 Census, in addition to demographic analysis, the Census conducted a Post Census Enumeration Survey (PES) in which undercount was estimated on a case by case matching of Census records with those obtained in the survey of 165,000 households. According to the PES, the undercount rate for Hispanics (5 percent) and reservation Indians (12.2 percent) were even higher than the rate for blacks (4.6 percent), but the extent to which the undercount for these groups is concentrated in particular age and/or gender groups is not known (Hogan, 1993). The PES undercount was 0.7 percent for non-Hispanic whites and 2.4 percent for Asian and Pacific Islanders.

CURRENT ISSUES IN THE MEASUREMENT OF RACE/ETHNICITY

Conceptualization of Race

Traditional explanations for health status differences between the races in the U.S. have focused on biological differences between racial populations. Nineteenth-century medical research, for example, attempted to document that blacks were biologically inferior to whites and therefor more susceptible to a host of illnesses (Krieger, 1987). Most current research on racial differences has abandoned blatant racist ideology but much of it still assumes that racial variations in disease are due to underlying differences in biology. The biological approach views racial taxonomies as meaningful classifications of genetic differences between human population groups. It assumes that race is a valid biological category, that the genes which determine race also determine the number and types of health problems that an individual will have (Krieger & Basset, 1986). The available scientific evidence suggests that race is a social and not a biological category. First, the concept of race developed long before modern valid scientific theories of genetics existed. Historically, race was a useful construct, not only for classifying human variation, but also for providing a rationale for the exploitation of groups that were regarded as inferior (Montagu, 1965). Second, the extant racial categories do not represent biological distinctiveness. There is more genetic variation within races than between them. Irrespective of geographic origin or race, all human beings are identical for 75 percent of known genetic factors (Lewontin, 1982). In addition, some 95 percent of human genetic variation exists within racial groups with relatively small and isolated populations such as Eskimos and Australian Aborigines contributing most of the between-group variation (Lewontin, 1974). Thus, our current racial categories are more alike than different in terms of biological characteristics and genetics and there is no specific scientific criteria to unambiguously distinguish different racial groups.

Moreover, single gene disorders account for only a small part of racial differences in health. Sickle Cell Anemia, for example, occurs more frequently in African Americans than the rest of the population. However, it accounts for only three-tenths of one percent of the total number of excess deaths in the black population and is thus not a major cause of the higher rates of disease for African Americans (Cooper & David, 1986). Sickle Cell Anemia appears to have been a protective biological adaptation to environmental conditions. It is not limited to African Americans but occurs at higher rates for persons who originate in regions of the world where Malaria was endemic (Polednak, 1989).

Race and SES

Since the discrediting of biological explanations, researchers have been giving increasing attention to the role of social class or socioeconomic status as a determinant of racial differences in health. Race is strongly associated with socioeconomic status and many researchers view race as a proxy for SES. Table 2 presents selected SES characteristics for the 5 OMB categories (NCHS, 1993). The overall patterns for racial/ethnic groups in Table 2 mask the considerable variation that exists within each of the categories.

The data on educational attainment reveal that blacks, Hispanics, and American Indians have considerably lower rates of educational attainment than whites do. Rates of high school completion for Asian and Pacific Islanders are comparable to those of whites with the APIs having even higher levels of college graduation than whites. The unemployment data show a similar pattern with APIs and whites having the lowest rates and with the rates being considerably higher for American Indians, blacks and Hispanics in that order. However, other data reveal that the unemployment rates for some Asian subgroups are also high. The 1980 unemployment rates were 20 percent for the Hmong, 15 percent for Laotians, 11 percent for Cambodians and 10 percent for Samoans (Takeuchi & Young, 1994). The median household income for American Indians ($19,865) is very similar to that of blacks ($19,758) and both groups have income levels that are considerably lower than that of the white population ($31,435). The median household level for Hispanics is higher than that of blacks and American Indians but lower than that of whites, while the Asian population has the highest level of median household income in the United States. However, Asian families are larger and have more earners per family than the total population.

Thus, the 1990 per capita income of Asians ($13,420) was lower than that of whites ($15,270) (Lin-Fu, 1993). The data on poverty also follows the now familiar pattern. The highest rates of poverty are found for American Indians and blacks. These groups have rates that are about three times that of whites. Hispanics have rates that are substantially higher than whites, but lower than those of blacks and American Indians. The rates for the API category are slightly higher than that of whites.

SES and Racial Differences in Health

Given this strong association between SES and race, it is widely recognized that racial differences must be controlled for SES. Adjusting racial (black/white) disparities in health for SES sometimes eliminates, but always substantially reduces these differences (Krieger, Rowley, Herman, Avery, & Phillips, 1993; Cooper, 1993; Krieger & Fee, 1994; Williams & Collins, 1995). However, it is frequently found that within each level of SES blacks still have worse health status than whites. This pattern suggests that although most of the racial differences in health are accounted for by SES, race has an effect on health that is independent of SES. That is, while there is considerable overlap between race and SES, race reflects more than SES and fully understanding racial differences in health will require researchers to move beyond the traditional approaches.

Several researchers have emphasized that the failure of the traditionally utilized SES indicators to completely explain racial differences in health reflects the interactive and incremental role of racism as a determinant of health. The construct racism incorporates ideologies of superiority, negative attitudes and beliefs toward racial and ethnic outgroups, and differential treatment of members of these groups by both individuals and societal institutions (Williams & Collins, 1995).

Racism can affect health by giving rise to racial discrimination at the individual and institutional level. The former is an important but neglected stressor that can lead to adverse changes in health status while the latter can result in the inequitable distribution of desirable institutional resources including medical ones. However, racism is causally prior to SES and exerts its most profound impact by transforming SES such that an equivalent value on a traditional SES measure represents important differences in social and economic circumstances for persons belonging to different racial groups (Williams, Lavizzo-Mourey, & Warren, 1994). For example, college-educated blacks are about four times more likely to experience unemployment than their white peers (Wilhelm, 1987). Even after adjustment for job experience and training, blacks are more likely than whites to be exposed to occupational hazards and carcinogens at work (Robinson, 1984). Table 2 had earlier noted large racial differences in income, but income disparities understate racial differences in household economic resources. Racial differences in wealth are larger than those for income. Thus, compared to whites at equivalent levels of income, blacks and Latinos have substantially less economic security and are less able to cushion a shortfall of income.

Heterogeneity of Racial Populations

An emerging issue in the assessment of racial and ethnic status is the need to collect sufficient information to examine the variation within each of the standard categories. The American Indian (or Native American) population is characterized by considerable diversity. There are more than 500 federally recognized tribes and entities. Death rates for American Indians also vary considerably from state to state with rates being higher in states that have a larger concentration of Indians. Moreover, considerable tribal specific variation often exists within a specific state. For example, within the state of New Mexico there are large tribal differences in prenatal care, low birthweight and infant mortality (Halason, 1992).

Although the API population in the United States is geographically concentrated, with almost 80 percent of all APIs residing in only 10 states, the API category lumps together persons coming from 28 Asian countries and 25 Pacific Island cultures (Lin-Fu, 1993). Each of these subgroups has its own distinctive history, culture and language. Not surprisingly, an overall value on a health status indicator for the API population hides the considerable heterogeneity that exists for subgroups within that population. For example, the API population in California has death rates of homicide and legal intervention for 15-24 year olds that is 17 per 100,000, but the rates range from 6 for Chinese Americans and 13 for Japanese Americans, to 54 for Samoans and 73 for the other Pacific Islander category (Suh, 1993). Similarly, while the API population has the lowest death rates of any racial group in the United States, Native Hawaiians have the highest death rate due to heart disease of any racial group in the United States (Chen, 1993), and the rate of liver cancer for Chinese Americans is four times higher than that of the white population (Lin-Fu, 1993). Similarly, while most Hispanics have a common language, religion, and various traditions, the timing of immigration and the incorporation experience in the United States have varied for the more than 25 national origin groups that make up the Hispanic group, such that each group is distinctive (Massey & Denton, 1993).

Researchers have also given inadequate attention to the variations within both the black and white population. The black population is characterized by cultural and ethnic heterogeneity that is predictive of variations in health status (Williams, Lavizzo-Mourey, & Warren, 1994). There is considerable ethnic variation in the white population but little recent research attention has been given to examining the extent to which these differences predict variations in health status.

Comparative Analysis

The 1991 Census of England and Wales was the first to utilize the question on ethnicity (Balarajan 1997). Seven preassigned codes were used in the census. These were: white, black Caribbeans, black Africans, Indians, Pakistanis, Bangladeshis, and Chinese. An additional 28 categories were developed in the census based on write-in responses under the "Black other" and "Any other ethnic group" categories. Many summary classifications used in the census data includes the seven preassigned codes plus three additional codes: Black others, Other Asian, and Other. In addition to the question on ancestry, a question on country of birth was utilized and over 102 categories were developed. The question on country of birth has been utilized in previous censuses.

Several recent health surveys in the U.K. have also included measures of ethnic group membership. The Health Survey of England which began in 1991 and focuses heavily on cardiovascular disease and risk factors for cardiovascular disease has included ethnic group membership in the survey. Similarly, the General Household Survey, a large annual omnibus survey, of about 15,000 households per year has included data on ethnicity and country of birth in recent years. The survey includes measures of self-reported illness, both chronic and acute, as well as of risk factors and socioeconomic status. The OPCS national morbidity studies carried out around the time of the censuses are a major source of information of ambulatory care utilization in the United Kingdom. In 1991, data were collected on ethnicity and country of birth so it is now possible to generate rates of utilization of general practitioners by racial and ethnic status. The major limitation of this study is that it involves only self-selected general practitioners and there are questions about both generalizability, as well as the recoverage of the racial and ethnic populations.

Data on patient care in the United Kingdom is available through the Hospital Episode Statistics system. This system collects data on all inpatient and out-patient hospital visits. In 1995, ethnic categories were included in this data system. It will thus become possible to examine rates of particular diseases, surgical interventions, severity, etc. by ethnic group status. Ethnic status is not collected on death certificates and it would require an Act of Parliament for the inclusion. However, country of birth has been collected on death certificates since 1969 so that it is easy to examine mortality rates for first generation immigrants. Similar to the U.S., there is a linked infant birth and death file in the U.K. but unlike the U.S., ethnicity is not collected at the time of registration of birth.

RECOMMENDATIONS

1. There is a continuing need for uniform assessment of race and ethnicity by government-administered health data collection systems as well as by the wider research community.

2. Given the heterogeneity of racial and ethnic

populations, there is also a critical need for the inclusion of identifiers for subgroups of the API and Hispanic populations on all surveys and forms in the U.S. The ten categories in the British Census appears to capture the key dimensions of ethnic heterogeneity given the size of these ethnic minority populations.

3. Racial/ethnic data should be routinely utilized in the design, implementation and evaluation of health studies and health programs. The availability of adequate data, especially morbidity data, for American Indians, Hispanics, and APIs is still a major problem. Because of the relatively small sizes of some of these population groups and their geographic distribution, standard sampling strategies for national populations do not yield adequate sample size to provide reliable estimates for the distribution of disease in these groups or to explore heterogeneity within a given racial group. Surveys focused on a particular geographic area with a high concentration of a racial subgroup as opposed to national ones are necessary to provide data for these groups. Combining multiple years of data in ongoing surveys is another useful strategy for obtaining health information for small population groups. This latter strategy can also be useful in the U.K. context in population-based health surveys.

4. Translate questionnaires and ensure that measurement instruments are culturally appropriate. Health researchers must also give greater attention to translating study instruments for persons who have limited proficiency in the English language. These persons are more likely to be members of racial minority populations. For example, in 1990, while only 8 percent of the total United States population was foreign born, 74 percent of APIs were foreign born (Lin-Fu, 1993). Currently, major federal health surveys, such as the Health Interview Survey, do not routinely translate the questionnaire into other languages. In addition to translating the survey instruments, researchers must also ensure that their new instruments meet the tests of conceptual, scale and norm equivalence (Takeuchi & Young, 1994). Conceptual equivalence refers to similarities in the meanings of the concepts used in the assessment. Scale equivalence is the use of questionnaire items that are familiar to all groups, while norm equivalence ensures that the norms developed for the targeted group is appropriate and not arbitrarily assigned from another.

5. Build communication mechanisms with racial/ethnic communities to ensure that they receive findings from current studies and have input in future research and

interventions.

6. Periodically monitor and update the current measures of race and ethnicity. Data collection forms should be revised to ensure consistent classification across data systems.

7. Whenever racial/ethnic data is reported, give more attention to interpretation: always indicate why race/ethnicity is being used, the limitations of racial/ethnic data, and how findings should be interpreted. The presentation of data on racial differences should routinely stratify them by SES within racial groups. Failure to do this may mis-specify complex health risks and even lead to harmful social stereotypes and consequences.

8. Move from studies of race and health to studies that identify the specific factors linked to race that affect health. Whenever feasible, additional information that captures these characteristics should be collected. This will include the assessment of SES, acculturation, and economic and noneconomic aspects of discrimination (Williams, 1997). There are limited opportunities to collect additional information in the vital statistics system and in record-based surveys. However, even in these contexts, years of formal education, nativity status and years since migration can be ascertained.

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Table 1
Racial/Ethnic Measurement in Selected Surveys and Major Data Collections
U.S. Department of Health and Human Services

Name	Data Source/Method	Uses of Data	Sample	Race/Ethnicity and SES	Periodicity
I. Population-Based Surveys					
National Survey of Family Growth (NSFG)	-Personal interview	-Contraception & sterilization -Teenage sexual activity & pregnancy -Family planning & unintended pregnancy -Adoption -Breastfeeding -Infertility	-14,000 women 15-44 years of age sampled to complete over 10,000 interviews -Oversample blacks & Hispanics	-OMB categories -4 Hispanic groups -Family and individual income and poverty level -Sources of income -Education & occupation	3 and 4 years (2000 and 2003)

National Health Interview Survey (NHIS)	-Personal interview	Annual data on: -Health status and disability -Utilization of health care -AIDS knowledge and attitudes -Family resources -Health insurance -Access to care -Immunization -Injury -Health behaviors -Functioning	-41,000 households -Oversample blacks & Hispanics	-OMB categories -4 Hispanic groups -Family & individual income & poverty level -Education & occupation -Type of living quarters -10 API groups	Annual
II. Record-Based Surveys					
National Hospital Discharge Survey (NHDS)	-Hospital records -Computerized data sources	-Patient characteristics -Length of stay -Diagnosis & multiple diagnoses -Surgical & diagnostic procedures	-542 hospitals -250,000 discharges	-OMB categories	Annual
National Survey of Ambulatory Surgery (NSAS)	-Abstract forms completed by facility staff	-Patient characteristics -Diagnosis & multiple diagnoses -Surgical and diagnostic procedures	-750 facilities -180,000 patients	-OMB categories	Annual through 1996; periodic thereafter

National Ambulatory Medical Care Survey (NAMCS)	-Encounter forms completed by physicians practicing in private offices	-Characteristics of patients’ visits to physicians -Diagnoses & treatment	-3,000 physicians in office-based practices -45,000 patient visits	-OMB categories	Annual
National Hospital Ambulatory Medical Care Survey	-Encounter forms completed by physicals and other hospital staff	-Characteristics of patients’ visits to hospital outpatient departments & emergency departments -Diagnoses & treatment	-600 hospitals -90,000 patient visits	-OMB categories	Annual
National Nursing Home Survey (NNHS)	-Long term care providers -Resident next-of-kin interviews	-Number & characteristics of residents in nursing homes (NH) -Functional status of NH residents -People discharged from NH -Expenditures of NH	-1,200 nursing homes -7,200 NH residents -7,200 NH discharges	-OMB categories	Historically every 4-10 years; converting to bi-annual cycle
National Home and Hospice Care Survey (NHHCS)	-Home health agencies and hospices	-Number of patients -Functional status of patients -Number of discharged patients -Characteristics of home health agencies & hospices & their patients	-1,200 home health agencies & hospices -7,200 current patients -7,200 discharged patients	-OMB categories	Annual through 1996, bi-annual thereafter
III. Vital Statistics System					

Vital Statistics Cooperative Program (VSCP)	-State vital registration	-Life expectancy -Causes of death -Infant mortality -Perinatal care & birthweight -Birth rates -Nonmarital births -Pregnancy outcomes -Occupational mortality -Teenage pregnancy	-All births, deaths, & fetal deaths -Counts of marriages & divorces	For births, deaths, & fetal deaths: -White, black, 5 API groups, American Indian, Other -5 Hispanic groups -Education -Births & deaths 10 API groups from 7 states & NYC Deaths only: -Occupation in 21 states	Annual
Linked Birth/Infant Death Program	Birth & Death Certificates	-IM rates by birth & period cohorts -IM rates by birthweight	-All U.S. births & infant deaths	-Same race groups at VSCP -Education	Annual
National Death Index (NDI)	State registration death certificates	-Facilitates epidemiological follow-up studies -Verification of death for individuals under study -Most NCHS surveys are linked to the NDI	-All deaths	-Same race groups as VSCP	Annual

Table 2
Selected economic profiles for the United States, 1990 Census

	American Indian and Alaskan Native	White	Black	Asian and Pacific Islander	Hispanic
Educational attainment (Persons 25 years and older):					
Percent less than 9th grade	14.2	8.9	13.8	12.9	30.7
Percent high school grad or higher	65.3	77.9	63.1	77.5	49.8
Percent bachelor's degree or higher	8.9	21.5	11.4	36.6	9.2
Employment status by sex (Persons 16 years and older):					
Percent unemployed, males	16.2	5.3	13.7	5.1	9.8
Percent unemployed, females	13.5	5.0	12.2	5.5	11.2
Household income in 1989:					
Median household income	$19,865	$31,435	$19,758	$36,784	$24,156
Percent below the poverty level by age:					
All ages	31.7	9.8	29.5	14.1	25.3
Under 5 years	43.3	13.8	44.0	17.5	33.4

Source: Department of Health and Human Services[N]

RESEARCH AND DEVELOPMENT ISSUES IN MINORITY HEALTH

by

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I. BACKGROUND

After World War II, minority communities were indeed a small, minute fraction of the nation's population, shunted to one side during the development of the modern American health care system from 1945 to around 1965. Because they were numerically so small, their particular health and behavioral profiles were not the driving ideas for this nascent system. These developing institutions were built around the norms of patient profiles and behavior encountered in the "mainstream" Anglo population, that was the overwhelmingly predominant majority during that period. Minority health research and delivery tended to be relegated to the margins of the effort of building and sustaining the modern medical research and delivery system.

Since that period, three monumental changes have occurred in the country, which make this affluent majority-deprived minority approach no longer viable:

1. Demographic change in the ethnic composition of the nation's population;

2. The emergence of population based medicine;

3. The emergence of population based budgeting for financing of health care delivery.

The effects of each of these changes will be explored.

Demographic Changes

The state of California offers a useful example of the demographic changes facing this nation. In 1950, during the height of the "Baby Boom", nearly 90% of the state's population was Anglo, and only 10% was ethnic minority. See Figure 1. The Baby Boom ended in 1964, leading to a drastic reduction in Anglo population growth . Fertility in minority (Black, Latino and Asian) populations, especially the Latino, was significantly higher than Anglo, leading to a greater rate of natural increase. At the same time, there were changes in immigration law. The "bracero" program, a program of contract labor established as an emergency World War II measure in 1942, expired in 1964. However, demand for Mexican labor continued. The country-based quotas used for assigning immigration visas, that had greatly favored European countries while restricting Latin American and Asian immigration, were abolished.

Immigration, especially from Mexico and Latin America, and later for various Asian countries, begin to increase. Immigrant Latinos had much higher fertility rates that U.S. Born Latinos. As a result of higher fertility and immigration, the Latino population grew explosively. See Figure 1.

It is estimated that by approximately 2004, the Anglo population of California will become less than 50% of the state's total, making California the first large state to achieve a "majority minority" population. The minority population of the state will continue to grow relative to the Anglo population, as indicated in Figure 2, until by 2040, 65% of the state's population (total 60 million) will be what we currently term minority.

These changes are not limited to California. The larger, industrialized states are all experiencing similar changes. In 1990, the minority populations comprised 40% of Texas, 40% of New York, 35% of Florida and 30% of Illinois population. See Figure 3.

These demographic forces are at work across the county. National projections show that by 2055, the United States population as a whole will be a "majority-minority" population. See Figure 4.

While it has been customary to think of minority populations as being relatively unimportant when researching the statistical "norms" of society, key states now need to understand minority health, and the rest of the country will need to within two decades, for these former minorities health profile and behaviors are now becoming the statistical norm.

Population Based Medicine

In the post War era, medicine in the U.S. was delivered around a solo, office-based provider, under a fee-for-service indemnity plan. This arrangement favored the medical focus on each individual patient. Since then, medical care organization has changed to large, managed care organizations, with a pre-paid enrolled population. Providers in managed care organizations now need to raise their vision, up from concentration on curing an illness in a particular individual, to the management of a disease condition over an enrolled population. The interventions need to be group level interventions, rather than strictly individual level. Rather than simply provide medical interventions for the control of heart disease of an individual, a provider now needs to learn how to manage heart conditions overall within the enrolled population for which she or he has responsibility.

The demographic changes impact population based medicine perspective by shifting the ethnic composition of the population from a largely Anglo one to a largely “minority’ one.

Population Based Budgeting

With increasing portions of the nation’s population enrolled in managed care, and an increasing proportion of that population composed of “ethnic minorities”, the financing of services becomes increasingly linked to the health behaviors and profiles of these minority populations.

A particular development that combines these three changes is the movement of medicaid funded patients to managed care. These patients, who are disproportionately minority, have in the past been shunned by private providers on a fee-for-service basis, as the reimbursements were not deemed sufficient. However, under managed care, these Medicaid patients suddenly represent one of the more lucrative patient bases. While five years ago the major problem with Medicaid covered patients was finding a provider who would see them, under managed care these patients are being very aggressively recruited.

II. PAST STRATEGIES AND APPROACHES

Current efforts in research and development on minority health are largely constrained by past strategies and approaches. A review of these strategies and approaches in the areas of data and theory will provide an understanding of needed future strategies and approaches.

Data

Definitions of Race/Ethnicity. The United States is one of the few industrialized countries to maintain detailed records by racial category. This practice was begun in the very first census (1790), to identify Black and Indian population apart from White for policy purposes, such as congressional representation. As the country grew in size and encountered other racial/ethnic groups (e.g. Latinos in the Southwest, Asian immigrants, etc.), legal sanctions were often associated with particular racial groups (residential and educational segregation, job discrimination, etc.) thus the identification of these groups was of interest to policy makers.

Racial categories were held to be separate and mutually exclusive: one could not be both Black and White, but one had to be categorized as either Black or white. The “one-drop” approach in many states held that a single Black ancestor anywhere in one’s genealogy was sufficient to categorize one as Black.

American Indian Ancestry was more nuanced, in that each tribal treaty with the U.S. government specified a “quantum level”, a specific proportion of ancestry needed to be counted as an Indian. On the one hand, this established a mutually exclusive “Indian/Non-Indian” dichotomy. On the other hand, the quantum level varied by treaty, so that under one treaty a person would have to be at least 1/4 Indian by blood, while in another a person might be as little as 1/32 Indian by blood, yet both could be counted as an Indian.

Latinos have not fit this racially dichotomous algorithm very well, for they are generally self-acknowledged “mestizos”, i.e. a racial blend that can include Indian, European, African and Asian ancestry. In the 1990 Census, when asked to identify themselves racially, most Latinos chose the racial residual category of “Other Race”, rather than the proffered categories of White, Black, Asian/Pacific Islander or American Indian. The unanswered question is whether Latino (Hispanic”) is a racial category or an “ethnic” category. While as recently as the 1930, Latinos were categorized racially as “Mexican” (which is technically a term of national origin, not race), in the 1940 census Latinos were coded racially as White. With the advent of the “Hispanic” identifier independent of race in the 1980 census, Latino data are reported with the proviso the “Hispanic may be of any race”.

There is a built-in limitation in the assumption that the racial categories are static and mutually exclusive. With the elimination of miscegenation laws, the rates of intermarriage between members of different racial groups has increased tremendously, leading the a growing population of “mixed race” children. The current practices of assuming mutually exclusive racial categories will not be practical in states such as California within a generation.

Incomplete Data. Because of the country’s linkage of race to legal standing for much of its history, detailed records of some populations such as Black and Indian were kept. Latinos have occupied a problematic place in this racial schema, leading to the abolition of Latino identifiers from the 1940 to 1970 censuses. Latino health data were simply unavailable until recently simply because the “Hispanic” category was not provided as an option. Even today, some states with large Hispanic populations such as Florida do not utilize Hispanic identifiers, nor do some large federal institutions such as HCFA.

Unrepresentative Studies. Because of sparse attention and sparse data, an unfortunate tendency has developed in which studies that were not meant to be representative of a particular minority population are, nonetheless, generalized out to the entire population. For example, studies of Black populations have tended to focus on ghettoized, urban inner-city, poverty stricken populations. Yet, the majority of the Black population has moved into the middle class, and out of the segregated residential patterns; they have been little studied. Likewise, anthropological studies of American Indians have focused on reservation populations, while in states such as California, the vast majority of Indians are urban dwellers. In a similar vein, until recently, a large number of Latino health studies dealt with either rural farmworker populations, or with gang-related violence. Use of larger, more complete data sets show that only 4% of the Latin population is rural, or that less than 5% of teenagers belong to gangs.

However, lacking population-based data on the minority group norms, these studies of relative outlier populations become generalized to the entire minority population. This is particularly prevalent in policy circles, for whom such short-hand social portraits found in an outlier population make compelling arguments, albeit somewhat misleading.

Theory

Equally as important as the data are the theoretical frameworks used to understand the data. Theoretical models used to explain minority health status and behavior have not progressed much since the 1960s, while the availability of better data have led many researchers to seriously question the utility of these old theoretical frameworks. A general shortcoming of these theoretical models is that they tend to be reductionistic, and overlook patterns of behavior that can positively influence health profiles.

Race-Specific Diseases. With the discovery of minority populations in the 1960's, an early attempt to jump-start research on their health care was made by focusing on race-specific diseases. Thus, sickle-cell anemia became identified as the Black disease, and diabetes as a Latino and American Indian disease.

While there is some utility to identifying genetically-linked diseases, these diseases are seen in many racial groups outside those primarily identified with the disease (other mediterranean groups suffer from sickle cell, and the Black mortality rates for diabetes are twice as high as Latino or American indian).

An over-emphasis on race-specific diseases may obscure the fact that most diseases are the product of behavior and familial genetics, not large-scale racial groups that, today at least, are extremely heterogeneous genetically: Blacks, Latinos and American Indians are primarily mestizo populations, and constitute racial/ethnic categories largely by executive fiat more than by internal genetic uniformity.

Structural Risk Factor Models. A different type of reductionist theorizing has been the structural risk factor models. The primary model is the socio-structural risk factor model, in which a population's level of education, income and access to care are the primary determinants of its health status. Of course, low income, low education and low access translate to poor health status; the worse the risk factors (lower income, education and access) the worse the health status.

Minority populations may be described as having lower income, education and access than White populations. Hence, the assumption has often been made that minority populations will have worse health indicators than White. The major research question has been whether it is the fact of minority status (which is often accompanied by high risk factors) or the risk factors independent of minority status that results in poor health outcomes. Research efforts have attempted to disentangle minority status from risk factors by controlling for risk factors. The results have been indecisive.

Urban Underclass. A related theoretical model comes from the urban underclass. As propounded by William Julius Wilson, the urban underclass is characterized by socio-psychological; characteristics, including low labor force participation, long term welfare dependency, low levels of family formation and health harming behaviors. Urban underclass populations are concentrated in urban, inner city areas, and are formed predominantly by minority populations.

Cultural Models

Another group of theoretical models are derived from studies of culture.

Traditional v.s. Modern culture. The cultural orientations of different groups are located along a continuum between traditional culture and modern culture. Traditional cultures are characterized as being passive, fatalistic, superstitious, parochial, present oriented and unable to defer gratification. By contrast, modern cultures are characterized as being active, scientific, rational, cosmopolitan, future oriented and able to defer gratification.

American Indians and Latinos in particular were often “proved” to be from traditional cultures. The conclusion is often drawn that these traditional orientations make American Indians and Latinos suspicious of modern medical care, and unlikely to seek care with physicians. In these models, Indian and Latino health seeking behavior will only be raised once the traditional Indian and Latino culture has been replaced with a more modern culture. This, of course, will be difficult.

Culture of Poverty. Popularized by Oscar Lewis’s work in Mexico and Puerto Rico, the culture of poverty posits a universal culture wherever poor populations are found. The key characteristics of this culture include:disintegrated families, loss of religious meaning, disorganized labor patterns. Using this framework, one might conclude that minorities, who have higher rates of poverty than anglos, would be more likely to be trapped in this culture of poverty.

Folk Culture. An offshoot of the traditional-modern culture models, this body of theory takes careful note of non-western medical healing practices and healers. Particularly used in studies of Indian and Latino health behavior, this approach has carefully catalogued the more exotic items of minority health behavior.

Black Folk Culture

Root doctor: a person who is skilled and knowledgeable in the use of herbs and other healing materials.

American Indian Folk Culture

Shaman: the use of shamans in medicine has long been a focus of anthropological work, in spite of the fact that Indians make many medical visits to physicians.

Latino Folk Culture

Folk illnesses. *Susto* (fright), *mal de ojo* (evil eye), *mollera caida* (fallen fontanel), *empacho* (food stuck to stomach), *aires* (sudden chills), and *nervios* (nerves) are some of the folk illnesses that have been regularly studied.

Folk cures. Herbal cures, the brewing of teas, the use of *limpias* (cleansings), *sobadas* (massages) the use of prayers and candles have often been noted.

Folk healers. *Curanderos* (healers), *parteras* (lay midwives), *sobadores* (masseurs), *hueseros* (bone setters) *yerberos* (herbalists) and *brujas* (witches) have all been studied.

The general tone of the folk culture approaches is that traditionally folk culture oriented patients so prefer these practices and providers that they would rather seek them out for an illness than western, modern medicine. This form of research suffers from an unwitting exoticizing of behavior, and drawing on unrepresentative samples to research particular ethnomedical practices.

III. INITIATIVES

Federal:

Uniform Federal-Level Data Collection. In 1973, the Office of Management and budget promulgated a series of definitions for different minority groups that were to be used for federal purposes. That directive operationalized a definition for Hispanic for the purposes of federal data collection. Although this definition has not been completely implemented--for example, medicare does not code for Hispanic--it at least set a standard.

NIH minority initiatives. The National institutes of health have, over the years, established a number of minority health initiatives, to stimulate research activity on minority health. Each institute has developed its own set of initiatives, with some being more active than others.

Research grants (R0-1) have been the major format for this funding. Fellowships for minority researchers are offered as an add-on to many R0-1 funded research projects.

Office of Minority Health. The Office of Minority health has been the most consistent on-going federal effort in stimulating work in minority health, particularly in the health manpower development area. Many of the initiatives undertaken by health professional schools in recruitment, admissions and curriculum have been stimulate, directly and indirectly, by this office.

SAMHSA (Substance Abuse and Mental Health Services Administration). (formerly, ADAMHA: Alcohol, Drug Abuse and Mental Health Administration)Through its divisions of Applied Prevention Studies and of

Community Education, SAMHSA has been one of the foremost researchers in minority communities that tend to be disproportionately impacted by substance abuse.

Centers for Disease Control (CDC). CDC was one of the lead federal agencies to research, and facilitate research, on HIV/AIDS in various minority communities. This was prompted by CDC epidemiological work that showed minority communities to be disproportionately impacted by HIV/AIDS.

State

Data Collection. With the federal level setting a standard for uniform minority data collection, states have followed their lead. As states can operate with a high degree of independence, not all states have opted to collect all their data with all the minority identifiers. Florida, for example, with its vibrant economic center of Cuban Americans, does not code for hispanic on its birth and death records.

University based research. With its collection of private and public universities, there is no national, or even state-wide, policy stimulating research and development on minority health. General research campuses were reluctantly prodded into supporting minority focused course work and research, the most medical and health campuses have yet to offer significant levels of activity. The Historically Black colleges and Universities are the major exception to this pattern.

Local

Each state is subdivided into units called “counties”. Public health policy is generally the responsibility of the county level, and they are usually allowed tremendous leeway in setting policy and programs. Generally, local levels are not involved in primary research activities. However, the local health jurisdictions do have responsibility for collecting basic vital statistics and reportable disease data.

Data collection. This high degree of local autonomy has been an obstacle to the uniform collection of minority related data, for the counties present a quilt-like pattern of interest in this issue. Some of the larger states have mandated uniform data collection at the local level, but again, the pattern is spotty.

Private Sector

Private Philanthropy. In the past, private philanthropy took the lead in initiating the early programs in minority health research and development. However, philanthropic programs are generally designed to develop an area of activity, and not to support it over the long term. The hope is that a pilot project will demonstrate its worthiness, and become formalized by legislative action. While that was once the case, recent political trends reflected in the Affirmative Action debate indicate that the body politic is not supportive of minority-specific programs during the 1990s.

Corporate Sponsorship. A new actor on the scene in the area of minority health research is the emerging role of private sector efforts. With the simultaneous emergence of population based medicine and minority market growth, private sector providers (physicians, HMOs, hospitals, insurers and pharmaceutical companies) have seen their bottom lines affected by their ability to provide health care in culturally effective manners.

IV. STRENGTHS AND WEAKNESSES

While the strategies, approaches and initiatives are varied at the federal, state and local level, there are some uniform strengths and weaknesses noticeable ion all three.

Strengths.

The fact of concentrating resources on minority health research has been a strength. Absent these efforts, we would know even less than we do today.

Weaknesses.

The weaknesses, however, have been many.

Senior researchers more competitive than junior. While this is a normal fact of academic research progression, the demographic fact is also that minority researchers tend to be junior, less experienced, and often in non-tenure track positions.

Research university based projects are more competitive than projects based in non-research based universities. Minority researchers are often based in smaller universities, or even in non-university environments. They simply function with less research support and with fewer colleagues than their competitors I research universities.

The result of these academic patterns is that much minority health research is performed by non-minority researchers. While in itself, this is not necessarily a fatal flaw, a major limitation is that new theoretical models have not been as quick to emerge as that would be if there were greater theoretical diversity involved as a result of greater researcher diversity.

While the involvement of private sector, corporate sponsorship is new and a welcome respite from the constant cut-backs from the public side, it is not an unmitigated blessing.

Private research on minority health tends to be more market research, drive more by an interesting penetrating the markets and enrolling subscribers, and less to understanding the underlying health processes and dynamics. In addition, at times privately sponsored research is proprietary to a single provider group, and not readily shared or made publicly accessible.

SUMMARY

In summary, the strategies and approaches to research minority health in the Untied States has been to assume:

a. That white, non-hispanic health profiles and behaviors are the norm;

b. That minority populations' health profiles and behaviors invariably depart from the norm, in negative ways;

c. So, research efforts focus on identifying and explaining negative deviances from the white, non Hispanic norm.

V. WHERE WE ARE GOING

Anglo Profile No Longer the Norm

The major difficulty with the general trend in minority health research, as summarized immediately above, is that the white, non-hispanic population is no longer the statistical norm. In los Angeles County (a local entity with 9.1 million residents), the Anglo population is only 35% of the county's total. As indicated earlier, in most major states, the white population will be a minority within the next decade or two. The notion that the White population profile sets the statistical norm against which other groups deviate will be unworkable early in the 21st century

No Single "Minority" Norm

As new definitions of the societal norm emerge, they will need to take into account the fact that there is no single "minority" norm. A quick glance at some key indicators from the state of California will demonstrate this.

Infant Mortality. Infant mortality varies widely from group to group, with Latino and Asian infant mortality virtually identical to White, and Black infant mortality significantly higher. See Figure 5.

Crude Death Rates. Population based medicine is driven by existing patterns of morbidity and mortality. Crude death rates provide an early indicator of the types and incidence of conditions likely to be found in a population based practice setting.

The crude death rates for diseases of the heart vary widely from the aggregated state norm, from a high of 695 for White to a low of 65 for Latino. See Figure 6.

Age Adjusted Death Rates. Part of the difference between the groups in crude death rates is the differential age structure. However, when adjusted for age, there is still significant variation. The age-adjusted rates for the same cause of death (diseases of the heart) show a range from 165 for Black to 80 for Latino. See Figure 7.

Hospital utilization. The differential mortality patterns have their echo in the differential hospital utilization rates. Again, these patterns vary tremendously by ethnic group. Overall per capita average hospital charges ranged from a high of for White to a low of for Latino. See Figure 8.

Culture key to behavior

These group differentials point research in the direction of seeking explanation in the area of culture, rather than simplistic genetic background. In particular, the case of Hispanics, who have the lowest income and educational level, yet also the lowest death rates and hospital utilization, indicate that their health profile cannot be explained by any of the major models outlined earlier (racial group genetics, culture of poverty, urban underclass model, traditional culture model).

STRATEGY RECOMMENDATIONS

Uniform Data collection

While a federal-level “gold standard” of ethnic identifiers exists, it has not been uniformly implemented. A necessary first strategic step will be to have it fully implemented at a federal, state and local level.

Within that mandate, the skyrocketing intermarriage rates will require that new categories be developed which will allow for multi-racial children to be properly accounted for.

New Theoretical models.

The inability of current theoretical models of minority health to explain the “Latino epidemiological paradox” points to a need for new theoretical models that can better capture the dynamics and processes of minority health.

Increased Research projects

The number of minority research projects funded by federal Institutes is still quite small. A sufficient knowledge base has to be built, and that can only be the result of large number of projects involving a large number of researchers.

Increased Minority Researchers

The quest for new theory will be greatly accelerated by the preparation of greater numbers of minority researchers. The training in research will need to be focused on population-based studies, so that the statistical norms for different minority groups may be understood, and outlier sub-populations be placed in proper perspective. In addition, the training will need to include the development of new conceptual models and theoretical paradigms to better explain variance in health status between the different minority groups, and the sub-group variance within each group.

With the exception of Asian American researchers, the growth of minority researchers has not even kept pace with minority population growth. Current policies limiting the use of Affirmative Action considerations in admissions to graduate and health sciences schools may negatively affect the preparation of minority scholars and researchers.

International Comparative Studies

While minority health has long been considered strictly domestic issue, the increased globalization of economies and the increased immigration flows from non-European regions suggest that theoretical breakthrough may now come form international comparative studies.

A COMPARISON OF U.S./U.K. EFFORTS

Formal workshop presentations, and informal discussions allowed an interchange of experiences about research and development issues in minority health. Work in the US is much further down the learning curve than in the UK. However, work in the US has had to enter many blind allies, and overcome many obstacles. These were shared with UK colleagues, in the hopes that they might avoid problems and pitfalls encountered in the past 35 years' experience researching minority health in the US.

Overall Strategy

The US strategy, for 200 years, has been to identify certain racial and ethnic groups in public data sets. Only recently in this lengthy history (since the mid-1960s) have inter-group disparities been seriously researched with an attempt to understand the dynamics of discrepancy. In the UK, the strategy has been, until recently, a race-blind approach, where data were not collected on particular racial/ethnic groups. The growth in size of the minority population has led to an interest in creating race and ethnic-specific data sets, but this has had to occur “in addition to” the general data collection efforts.

Policy Relevance

One of the founding principle of the NHS was the provision of health services to all on the basis of clinical need, regardless of ability to pay. The move away from a completely nationalized system to a “managed competition” system, whereby local Authorities contract for services, has raised the issue of the relationship between ethnicity and health in particular authorities. The policy was to provide data on this relationship to assist the Authorities in developing activities appropriate for a local area.

The US operates on a market-driven system, with public services being considered the “provider of last resort”. Until the Civil Rights Movement, racial and ethnic identifiers were more often used to exclude service utilization. Since the mid-1960s, changes in the medical care industry have led to the development of large-scale provider corporations (e.g. HMOs, IPAs, etc.) with more of a focus on populations than in the past. Interest in ethnic health outside the public sector is increasingly driven by market forces rather than principled dedication, but serves the same end: large corporate providers need to learn how to market and provide services to a diverse population.

What Works

Basic Demographic Data. While US Census data have been meticulous in identifying some racial/ethnic groups over a period of time, UK data have not had a lengthy history of similar data collection. Without population-based demographic data, rates cannot be computed. A special census was undertaken in the UK in 1991, by the Office of Population Censuses and Surveys to provide both population estimates and population characteristics.

Uniform Identifiers. Uniform comprehensive racial identifiers have been lacking in US data until recently. While such indicators do not always distinguish between sub-groups (e.g. Koreans and Vietnamese instead of just Asian/Pacific islander, or US born Mexican and Salvadoran immigrant instead of just Latino) nor are they uniformly applied everywhere (e.g. Florida still does not code for Hispanic) there are sufficient data to provide large-broad brush-stroke portraits of health profiles. The use of such indicators is new in the UK, and even broad-brush stroke portraits are in their initial phases.

What Doesn’t’ Work

Confusion in Terminology. In both the US and UK, there is still considerable confusion about the proper terms to use for different groups, and their proper operationalization. The US has in the past been meticulous in identifying a few specific racial groups, However, the largest, fastest growing group is Latino, which is not necessarily a racial group. Hence, there is still confusion about terminology and operationalization for this group. In addition, the increase in intermarriage rates have outstripped the ability of agencies to identify the offspring of such unions.

In the UK, data are kept for country or area of origin, but not necessarily for racial group. Thus, immigrants from East Africa may be largely East Indian in a cultural sense, while those from West Africa may be largely Black African, but white populations resident in those areas would also be included in the two categories.

The terms used in both countries may allude to:

-race

-ethnicity

-country/area of origin.

Epidemiologically, these may be very different types of populations.

Best Practices

Timely Information, Even If Incomplete. While there are many methodological issues still being resolved, there has been a push in both countries to create and release timely data. The report Ethnicity and Health in England was released, knowing that there were many data gaps. Likewise, data in the US on minority health are released at the federal and state level, with the full realization that there are many holes. The interests of society are better served by wide dissemination of data, even if spotty. Certainly policy decision are better served by some data rather than by no data.

Recommendations For Future Actions

Black and minority populations are currently 6% of the U.K. population. It was pointed out that in 1950, minorities were only a slightly larger percent, 9%, of the US population. The demographics in the US have changed that so that nearly 1 in 4 Americans are minority, and projections are that by 2050, the White Non Hispanic population will be a minority in the country. It is quite possible that there will also be sizeable minority growth in the UK.

Some districts and boroughs in the UK are already heavily black and minority. Brent and Newham were 45% and 42% minority, respectively. There are twenty districts and boroughs that are 19% or more minority.

In the US, many cities are already predominantly minority, and early in the 21st century, major states such as California and Texas will have majority-minority populations.

The two countries have much to teach one another about research and development in the area of minority health.

PRIMARY CARE: CHOICES AND OPPORTUNITIES FOR RACIAL/ETHNIC MINORITY POPULATIONS IN THE U.S. AND U.K.: A COMPARATIVE ANALYSIS

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INTRODUCTION

Persistent challenges in addressing the health disparities of racial/ethnic minorities are a concern not only in the United States (US) but also in the United Kingdom (UK) To improve the health of their respective racial ethnic minority populations both countries have undertaken a cooperative effort, spearheaded by the leadership of the Office of Minority Health (OMH), Office of Public Health (OPHS) in the U.S. Department of Health and Human Services (DHHS), together with the British Department of Health. The purpose of this joint collaboration is to identify and draw upon the experiences and lessons learned from both countries and to develop an agenda for closer US/UK health ties as together, these two nations struggle to meet the health needs of their racial/ethnic populations. The focal point of this endeavor to date, has been a bi-national conference, "Health Gain for Black and Minority Ethnic Communities," held in the UK from September 16-19, 1997. U.S. and U.K. conference participants, representing both public and private sectors, shared and discussed strategies and approaches used in each country to address specific themes and issues related to minority health.

Health professionals and policymakers in both countries, all agree, that the more effective strategy for health service delivery to a diverse population lies in primary care.(1-4) Moreover, if primary care is to be a successful national health delivery strategy, it must take into account the specific needs of black and minority ethnic people (5). While there is clarity regarding the need for continued development and implementation of primary care, there is considerably less consensus as to the definition or components of primary care.

Primary care has many meanings but almost everyone would agree on the following major characteristics. Primary Care involves clinical or personal health care of ordinary, simple conditions that are found in a specific population. As a result, Primary Care as a health service delivery strategy is ideally suited to diverse racial/ethnic populations. In the U.S., primary care practitioners assume responsibility for assessing health needs, planning and coordinating care and making appropriate referrals to other levels of care. These services are usually delivered to a defined population, in an easily accessible location within the community being served and includes outreach and education, health promotion and disease prevention as well as rehabilitation services. (6)

During the 1960s and 1970 primary care evolved into Community Oriented Primary Care (COPC), a variation of the basic patient/physician primary care relationship that had been the foundation of medicine for centuries. The six essential components of COPC are:

- Complementary use of epidemiological and clinical skills
- Responsibility of provider for a defined community
- Programs designed to deal with the health problems of the community or its subgroups in the primary care framework
- Community involvement in both governance and implementation of the practice
- Geographic, fiscal and cultural accessibility
- Integration of curative, rehabilitative, preventive and primary health care. (7-8)

Probably the most troublesome of these components in terms of implementation has to do with community involvement. Community participation can mean different things to different people. It can range from a simple, less powerful patient advisory board to a more powerful, consumer majority, governing board which was written into the legislation that established all Federally funded community health center primary care programs. Despite the difficulties involved in community participation, there is evidence that community involvement has been instrumental in assisting health professionals to not only identify community health needs but also to design, implement and evaluate interventions.(9)

In a recent article by U.K. researchers, primary care referred to the services provided by general practitioners and their primary care teams of dental general practitioners, pharmacists and community nurses.(10) However the authors also explained that in 1990 the Contract between general practitioners and the British National Health Services (NHS) reforms, expanded the roles and functions of General Practitioners (GPs) and their teams to cover the services they customarily provide as well as the purchase of secondary care on behalf of their registered populations. This expanded role was based on the assumptions that through 'primary care-led NHS', decisions taken about health care will move closer to patients and local people, and thus be more responsive to the their needs. It appears that there is considerable convergence in both the U.S. and the U.K in terms of not only the components of primary care but also with regard to the development of systems that invite and encourage community participation.

The purpose of this paper then is two fold. The first and most important task is to conduct a comparative analysis of the strategies and approaches employed by the U.S. and the U.K. as they continue to develop and implement primary care. The focus will be to identify strengths and limitations, what works/does not work and why, best practices and lessons learned, particularly as it relates to their ethnic minority populations. The final objective of this paper will be to present some opportunities for collaborations and to make recommendations for future action.

I. COMPARATIVE ANALYSIS OF PRIMARY CARE STRATEGIES AND APPROACHES IN THE US. AND UK.

Preamble

Before proceeding to make any comparisons or formulate any analysis of the development of primary care strategies and approaches in the U.S. and the U.K., some discussion is in order on two specific issues. First, there are several risks and benefits to the comparative approach, especially when the convergence of policy outcomes between the two countries are considered. Too many researchers have conducted studies, with political overtones, whether pro or anti socialized medicine, that described the U.S. system as a failure and characterized the British system as successful by default.(11) Second, and this is actually a caveat that must be issued here. Namely, that we can not presume to fully compare the development of primary care in two countries that essentially are quite different in terms of population size, racial / ethnic groups, social, economic, political and institutional structures and data collection methods. At the same time however, there are tremendous similarities in the fundamental focus and goals of health policymaking in both countries (12). As a result, the goal of this comparative study will be much more in keeping with an effort to identify those factors that are unique or specific to the health care institution at work in each country, what works, doesn't work and why, best practices and lessons learned, as opposed to what is common to any one type of health care system.

Analytical and Organizational Framework

Having said that, we come to the business of analysis. To study and compare the development of primary care choices and opportunities for racial/ethnic minorities in the U.S. and U.K. is essentially to study a social problem, which suggests the need to use a sociological approach. In that context, the social problem of developing, enhancing and implementing a primary care delivery system that can meet the diverse needs of everyone in the population, including racial and ethnic minorities is best as part of the social structure in which it occurs. Here, social structure refers to the many aspects of how a society is organized, including social roles and positions such as laborer, wife, doctor, patient, etc. Social structure also includes the expectations and rewards of those various roles and positions, as well as the different kinds of relationships among those different positions and among different groups of people who share a common position in society whether historically, politically, economically, and otherwise. The idea here is that the behavior of individuals or groups of individuals is largely influenced by the type of social structure their society has and their position in that social structure.(13)

Social structures are complex entities and as such there are a variety of theoretical approaches used in studying them. For our purposes, we will rely on two major theoretical perspectives: systems theory also known as the functionalism or order perspective and its opposing view, the conflict perspective. Each comes with its own set of assumptions. Systems theory says that a social structure is efficient because it is made up of interdependent parts. The interconnection among all parts of a society helps to create a consensus about a set of central beliefs and values that most people in the society accept. As a result change occurs only incrementally and when change occurs it has a ripple effect because of the interdependence of the system. This means that systems tend to focus on maintaining a stable state. Therefore, change does not occur from within but almost always must be stimulated from outside.(14) In other words societies do not establish particular sets of policies by chance. Rather, they develops certain policies because those policies were useful to that society at that time for that particular situation. (15).

At first blush, the conflict perspective appears totally opposed to systems theory. A basic assumption of the conflict perspective is that there is an unequal distribution of scarce resources such as wealth and power and so the "haves" or "elites" want things to stay the way they are and the "have nots" want social change. The "haves" being the more dominant group are in a better position to control the economy, politics, religion, mass media and the way history is recorded. In that respect they can control the values and beliefs of the masses even when the interests of the masses are hurt by those beliefs and the beliefs are only useful for the dominant groups. Karl Marx described this situation as the creation of "false consciousness."

Upon closer examination of both perspectives it becomes evident that they are not that different. Essentially, each perspective argues that societies adopt the policies they do because these policies are in some way useful. Consequently, the only remaining question between the two perspectives is, useful for whom? (16). If indeed the two perspectives are not that far apart it appears prudent for us to consider both of them in our analysis. After all, it is quite possible that the ways in which primary care has been developed and implemented in the U.S. and U.K. are both, at one and the same time, useful for maintaining the stability of these respective systems and for promoting the self interests of the "haves' at the expense of the "have nots." (17)

Using the two perspectives detailed above as the theoretical under-pinning, we can now define a set number of distinct dimensions within which we can conduct some analysis. In that regard this study will be specifically anchored in three spheres of analysis: historical, social and political/economy contexts. Taken together, the theoretical basis and the distinct spheres of analysis, provide an organizing framework for this study.

A. HISTORICAL DEVELOPMENT OF PRIMARY CARE IN THE US. AND UK.

1. The U.S.

The development of primary care in the U.S. has been a slowly evolving process for well over a century, with incremental implementation across the nation.(18) This halting advance of primary care has been due to a variety of factors. Primary Care, with its community driven solutions for creating health social and economic benefits for everyone is perceived as being incompatible a health care industry that is market driven, operated as a private enterprise with minimal involvement from the federal government and, in more recent times, more focused on costs than on care (19). Despite this conflict, as early as 1871 primary care services were being delivered in community dispensaries. The dispensaries began to proliferate because they were the major form of medical care available to the urban working class. However, physicians soon mounted an attack against them, which led to: 1.) the demise of dispensaries by 1920 and 2.) the beginning of a two class system of health care in the U.S., one for the poor and under- or un-insured and one for the wealthy and insured. (20) Undaunted, primary care advocates in government moved on, very quietly, to offer a limited amount of preventive and primary care services especially to the poor and managed to survive as they were not perceived as trespassing on the American Medical Association's clear separation of public health (government responsibility) versus personal health services (private enterprise). (21)

The Federal role in primary care, began its evolution with the Migrant Health Act of 1962. That act and its subsequent amendments are significant pieces of legislation for two reasons. First, the Migrant Health Act represents the Federal government's response to public outcry over the conditions of migrant farm workers. It provided Federal grants to support clinics providing services to domestic migrant farm workers and their families. Second, this 1962 Act marked a radical departure from historic non-involvement and launched Federal involvement in primary care policy and service delivery.

The following year, the Office of Economic Opportunity (OEO) was created. By 1965, the OEO recognized the importance of adequate health to the overall issue of poverty, and funded the Neighborhood Health Center (NHC) program. Initially, The NHC was established as a demonstration project. It was designed to meet the basic characteristics of primary care which meant that it had to offer an array of personal health services that are accessible and acceptable to the patient, comprehensive in scope, coordinated and continuous over time, and for which the practitioner is accountable for the quality and potential effects of services. NHCs were intended to provide services to poor, inner city, largely black and Hispanic residents as well as the whole population and by the end of 1968 OEO had funded 52 such centers. (22). The NHC survived attacks from doctors and their allies in the Nixon and Ford administrations to become institutionalized in 1975 as "community health centers" with their own legislative authority. The program expanded under the Carter administration and was later renamed the Community and Migrant Health Centers program.

The Bureau of Primary Health Care

Today the Community and Migrant Health Center program is one of 16 programs operated by the Bureau of Primary Health Care (BPHC). These programs are spread across the 10 public health regions of the continental U.S. as well as the islands of Hawaii, Puerto Rico and the U.S. Virgin Islands. Much of the responsibility for the delivery of primary care services across the nation rests with the Bureau of Primary Health Care(BPHC) located in the Health Resources and Services Administration (HRSA), one of eight agencies of the Public Health Service (PHS) in the Department of Health and Human Services (DHHS).

The mission of the BPHC is to increase access to comprehensive primary and preventive care. Its programs are designed to overcome financial, geographic cultural and organizational barriers to access to health care. These are the only Federal programs that accomplish this in a comprehensive way at the community level. As such they are an essential part of the Nation/s safety net for underserved and vulnerable populations including racial/ethnic minority populations. BPHC programs are implemented in collaboration with BPHC supported State Primary Care Offices and State Primary Care Associations in each state. The partnerships formed by BPHC with States and local communities contributes to the development of primary care programs that can meet the needs of defined populations in specific geographic locations and increases the availability of primary care services in racial/ethnic minority communities. (23)

Although these primary care programs survived the Reagan administration, he did succeed in transferring responsibility to the states for: greater involvement in the administration of the community health center programs; local health services planning; a greater share of Medicaid costs and a "basic reversal in U.S. federal health policy.(24)

Financing and Access Issues

Rationing of health care in the U.S. is accomplished financially. (25) Access to regular and ongoing health care in the U.S. is contingent upon possession of health insurance whether public or private which is often connected to one's employment status or the lack thereof. Out of pocket cost of private insurance are extremely prohibitive. Eligibility for Medicare the health insurance program for the elderly usually begins at age 65 and eligibility for Medicaid the publicly funded health insurance for the indigent is based on stringent guidelines for means testing that have now become even more rigorous as a result of Welfare Reform. It must be explained that the uninsured are actually two different groups. There is the never insured and there is the part time or sometimes insured. These are the working poor whose low income jobs do not come with insurance neither do these jobs pay enough for people to purchase insurance on their own.

It must be acknowledged that federal/state programs such as Medicaid have been instrumental in securing greater access to health care for the poor. In fact improved longevity rates and infant mortality rates among blacks in the U.S. who are three times more likely to be poor than whites provides evidence of the value of greater access to health care. Nevertheless, primary care as a strategy for health services delivery in the U.S. continues even today to be distributed along socio-economic lines. In other words most middle class people get their health care from a private practitioner operating alone or as part of a group. This is their regular personal or family physician who makes referrals to specialists as the situation requires and keeps a record of their medical history and treatment. Poor people on the other hand seek care in clinics whether hospital based or Medicaid mills or in emergency rooms with very little continuity to their care. (26)

In summary, Medicaid has indeed provided the poor with access to care. In addition the programs of the BPHC are an essential part of the Nation's safety net for underserved and vulnerable populations. However, collectively BPHC programs only serve one-fifth of the Nation's underserved populations. Between 1994-95, the number of persons not covered by public or private health insurance jumped from 37 to 41 million.(27) In 1992, estimates of the underinsured were as high as 50-80 million. (28) In 1995, Medicaid, the Federal/State health insurance for the low income population covered 33 million people which at the time was only 46% of those under 200 % of poverty. This situation is made even more difficult to fully analyze because of variation from State to State. (29)

Since the States and local governments have to deal with the problem they have begun to take action, some of which is of course politically motivated. George Pataki, Governor of New York State recently announced in a televised speech, plans to make universal primary health care available to all children from birth to 18 years of age. That this results from election campaigning is irrelevant if the outcome is that individual states begin their evolution towards developing access to primary care services for everyone including racial and ethnic minority populations.

Managed Care

The latest wrinkle in the development of primary care is to be found in Managed Care. Within the last 7-8 years, the U.S has experienced an unprecedented and accelerated shift towards a health financing system called managed care. In many ways a misnomer, managed care, with its capitated financing scheme, manages costs and so is embraced by both public and private health insurers as it allows them to develop predictable budgets based on monthly fixed capitated rates per patient enrolled in a managed care plan.

While managed care is being hailed as "the answer," a critical issue is that managed care is only available to those who are insured. A serious concern is how will it affect the health of racial and ethnic minorities who are disproportionately found amongst the poor, and the unemployed or in low income jobs which means they tend in greater numbers, to be uninsured, underinsured and in worse health than the mainstream population.

2 . The U.K.

The British National Health Service Act of 1946 has it roots in the National Health Insurance Laws (NHI) enacted in 1911. The NHI insured all low-income workers, but not their dependents, and guaranteed the insured the care of a physician plus free drugs until death To be sure, the NHI was not perfect. It did not cover services of a specialist, independent workers were all but excluded from coverage even though their wages were not much higher than that of a factory worker. It did not cover hospitalization, after care, X-rays or physiotherapy, treatment for tuberculosis or orthopedic appliances and artificial limbs (30)

Nevertheless, it was a beginning and viewed by a large segment of the British as a welcome system for providing health insurance that was more dignified than Poor Relief. For the very same reasons that the NHI signaled an end for many people to the Elizabethan Poor Law approach to dealing with poverty and illness, it was considered revolutionary and deemed unpopular by conservative-minded people. The British Medical Society (BMS), after calling for a vote on the NHI amongst its members, initially issued statements that doctors in Britain refused to participate, on the grounds that the NHI represented too much government control and interference and limitation on their income. However, the majority of British doctors, whose incomes were pretty low in the early decades of this century, began to defect and one by one joined the NHI. The BMS later rescinded their statement (31)

During the second world war Britain established a wartime Emergency Hospital Scheme which not only nationalized the majority of hospitals in the U.K. but also vastly improved the quality of hospitals, and the level of technology available to treat illness and disease.(32) Although the emergency conditions ended with the war it was successful in proving to the British what could be accomplished by the central government with planning and financial assistance. In 1942 a paper was published by the economist Lord Beveridge in which he proposed reforming the NHI and provided a blueprint for the National Health Service. (33) Conditions were therefore ripe in Britain right after the war, in terms of the attitude of the British, their recollections of the depression years of the thirties, the prospect of a more secure future. This all coalesced into Parliamentary action that gave Central government the freedom to design national health policy. While the National Health Service (NHS) legislation was being debated and discussed in Parliament as a bipartisan project, the Labor Party came to power and the newly appointed Minister of Health, Aneurin Bevan, a Welshman, who had climbed out of poverty and the coal mines and was committed to making the new NHS a reality. Within a matter of weeks after the NHS became law, the British Medical Association (BMA) opened up hostilities against the government, declaring non-cooperation. The actions were fueled primarily by the more affluent suburban doctors and specialists whose practices were based on fee-for-service. The majority of doctors, the GPs who already had a registry of patients through the old NHI and whose incomes depended on the capitation payments for these patients were much more supportive of the NHS. (34) To avoid a split amongst it members, the BMA was forced to accept the NHS but certain factions within the association would continue to fight for the protection of private medicine for more than another decade.

The new NHS began operation on July 5, 1948 and was administered in three separate components. There were regional hospital boards responsible for care delivered in hospitals, the Executive Councils, were responsible for the pharmaceutical, dental and eye services together with the medical practitioner services. Finally there was the local health authority, also known as the county or county-borough council with responsibility for the care provided by GPs/ family doctors in local health centers to the patients on their lists. In essence then, given the organization and administration of the NHS it appears that the NHS was founded from it's inception to deliver a basic package of primary care services to all of the British people.

NHS Reforms

The NHS has not been a static experience, it has undergone changes and modifications with time and experience. By the 1980,s the system suffered from being overloaded. Morale problems were rife throughout the system, nurses went on strike for better working conditions and protection of their professional interests and there were long waiting lists for surgery.(35) In 1988 the Thatcher government ordered a review of the NHS which was published in a White Paper in 1989 that became the basis for NHS reform legislation. The NHS reforms was politically costly for Thatcher her job as it was viewed by many as a further attempt on her part to raise taxes and privatize yet another state-run enterprise. (36)

The NHS reforms were implemented in 1991 and involve three major changes. With regard to hospitals the reforms allowed the larger hospitals to become self governing trusts. This means that they no longer report to the district health authority but continue as part of the NHS with more autonomy over their own operations. In this new arrangement the district health authority will no longer provide care but instead will purchase care from hospitals in the regular NHS system, the private sector or the newly formed NHS self governing trusts, whichever is better in terms of both quality of care and price. (37) The introduction of the 1990 Contract between GPs and the NHS reforms maintains the principal characteristics of British primary health care but extends the roles of GPs and their teams. GPs with large practices were given their own budget which could now be used not only to only provide care but also purchase secondary care on behalf of the population registered with them.(38) Finally the 1990 NHS and Community Care Act promotes care in the community by giving the local authorities responsibility for purchasing home care services. It is in community care, especially for the elderly, that need is expected to increase greatly as we enter the new millennium, because of an aging population. (39)

These reforms had at their base some fundamental objectives especially the creation of internal markets within the NHS that would stimulate competition as a tool for controlling costs and improving efficiency. However our interest here is with the effect of the reforms on primary care. The basic assumption behind changes in the role of the GP is that in a more primary care-led NHS, decisions about health care would move closer to patients and local people, and thus be more responsive to their needs.(40-42). The reforms are now well under way and today the NHS is fully aware that the move to develop a primary care-led NHS will fail if the specific needs of black and minority ethnic people are not taken into account.

3. THE ANALYSIS

Unquestionably there are notable differences and similarities in the historical development of primary care in the U.S. and U.K. Primary care in both countries developed from the basic assumption that medicine would continue to make tremendous progress in its capability to improve quality of life.(43) In both countries primary care has moved closer towards community involvement and is expected to continue advancing in that direction. They differ in terms of the level of implementation as there were antecedents in the U.K. that allowed for a national program of basic services from the start, while the U.S. programs have only been able to serve one fifth of the Nation's underserved population.

They also differ in that central government in the U.K. controls spending with pre-planned budgets in the U.K. In the U.S. health care costs as a percentage of the Gross National Product is expected to rise to 17% and to exceed a trillion dollars by the year 2000.(44)

From a functionalist or systems perspective the slower evolution of U.S. primary care programs has been useful. It maintained stability by providing primary care services to some but not all of the urban and rural poor including racial and ethnic minorities. In fact, because it was limited, it was not perceived as a serious threat to hospital based specialty care which was widely available to the middle class. Americans came out of W.W.II feeling exuberant, ready to grow the country, and all parts of the economy including health insurance and health care.

By comparison, and again from a systems perspective, the more comprehensive development of primary care in the NHS was useful in Britain because there was already in that system antecedents such as their NHI program. In addition the NHS had the support of British public opinion, who were War weary and needed to look toward a brighter horizon.. And if that was not enough, the Labor Party came to power. Plus, the small number of elite doctors in the U.K. who felt that the NHS was not in their best interest, could not hold their position of non-cooperation together, could not sway British public opinion and eventually had to acquiesce. All of these historical events created a window of opportunity in which establishment of the NHS served a stabilizing function for the entire society and at the same time was in the self interests of the majority of the doctors and as such, it was useful policy.

When we compare the development of primary care in the U.S. and U.K. from a conflict perspective, it is also evident that the way primary care developed in the U.S. was useful for those with wealth and power. Many of the those among the powerful and wealthy were themselves doctors, health administrators, chancellors of medical schools or health philanthropists who helped to build some of the famous specialty and teaching hospitals in the U.S. today and the medical schools attached to them. Within the first two decades of this century, medicine in the U.S. had transformed itself, through the American Medical Association into a formidable group with the highest level of expertise power in the society. The trustees and executives of the AMA and the members of its House of Delegates had been successful in weaving a highly organized and powerful self interest group. As medicine grew so did the power, wealth and prestige of this elite group. It simply was not useful to them to favor a comprehensive, nationally funded primary care strategy, employing salaried doctors, for delivering health care in the U.S. The history of the development of primary care policy in the U.S. did not happen by chance. Rather, the way in which U.S. primary care has evolved, was at one and the same time, useful for maintaining the stability of that social system and at the same time promoting the self interests of the more powerful, at that time.

However, the health care environment and the times are changing in both countries. After WW II, the health care system in the U.S. revolved around hospitals, with its ever increasing sub-specialties and technology which must be duly credited with many great life extending and saving achievements. However that technology and the advancements it delivered came at a price. Probably the most detrimental are two that we still struggle with today: 1) escalating health care costs which are projected to rise to 17% of Gross National Product GNP and to exceed a trillion by the year 2000 (44) and an ever increasing distance between patient and physician.

Given the current direction of the new primary care-led NHS and the ongoing development of primary care programs in the U.S. there appears to be some areas of convergence between the two systems. Currently, both nations are now fully aware that further development and implementation of primary care is contingent on them addressing the racial and ethnic health disparities each of them face and if they are to do so they must address the specific health needs of their various racial/ethnic populations. Both nations are adapting different versions of managed care market forces in order to hold health care costs down. While the strength of the NHS has been long terms relationships between patient and doctor they are looking to strengthen that even further and in the U.S. many individual states through BPHC programs with its Federal/State/Local government partnerships and other strategies are attempting to do the same thing by inviting greater community participation.

It is interesting to note that Clem Bezold, President of the Institute for Alternative Futures, predicted in November at the Healthy People 2010 Development meeting in Indianapolis, that not only will there be greater proliferation of primary care programs in the U.S. but also an increasing trend toward community participation in the design of primary care programs as we enter the next millennium.

B. THE IMPACT OF SOCIAL STRUCTURES ON THE DEVELOPMENT OF PRIMARY CARE SERVICES FOR RACIAL/ETHNIC MINORITIES IN THE US/UK:

1. THE U.S.

The ethnic composition of the population of the U.S. provides a good starting point for examining the social structure of the U.S. According to U.S. Census data the breakdown of the population by race and Hispanic origin is as follows: Blacks=13%; American Indian and Alaska Natives(AIAN)=1%; Asian & Pacific Islander Americans (APIA)=4%; Hispanics =11% and Whites 71%.(Figure 1) As recently as 1990, Whites were 76%; Hispanics were 9%, APIA were 3% and Blacks were 12%. Going back a little further to the middle of the century, Whites were 90% and Blacks were the only other group of significant numbers. These changing demographics are the result of changes in U.S. immigration policy between 1965 and 1990 which for the first time allowed the entry of large numbers of people from non-white regions of the world. As a result, not only has the U.S. become more racially diverse, there is also much variation between and within the different racial/ethnic groups in terms of language, culture, and health seeking behavior.

More than a decade ago, the Report of the Secretary's Task Force on Black and Minority Health , (45) sometimes referred to as the Heckler Report, unequivocally documented for the nation that:

- the health status of four distinct subgroups: African Americans (Blacks), American Indians and Alaska Natives, Asian and Pacific Islander Americans and Hispanics was disproportionately worse compared to Whites.
- Members of these groups had higher mortality rates on all of the leading causes of death namely heart disease, cancer, hypertension and diabetes
- there is greater morbidity for these groups in terms of substance abuse and violence
- several of these subgroups have higher rates of teen pregnancy, and out of wedlock pregnancy

The role of race/ethnicity, class and minority group status

Subsequent to the Heckler Report, several studies have shown that the highest rates of poverty (Figure 2. Poverty by Race) are concentrated among the same U.S. sub-groups of non-white people who are also those with disproportionately worse health status. (46-48)

While poverty or income level tends to be an accurate barometer of class, other tested measures include education. When education, (Figure 3, Education by Race) is used as a measure of social class, it has consistently confirmed that health status tends to be better for the more educated. (49-50). Here again, the groups with the least education are also the ones with the least income and the same ones that have been identified as being in poor health.

With regard to income, racial ethnic group members are found in much larger numbers in the lower paying-lower skilled jobs than Whites and in much less numbers in the higher paying-high-skilled jobs. (Figure 4, Percent Employed persons by race and ethnic origin & type of occupation)

In other words, the health status of racial and ethnic minorities in the U.S. is a function of the very structure of U.S. society in which minority group status refers not to the numerical quantity of that racial ethnic group but to the social class of the group. That is to say, minority groups are those who have less than its proportionate share of scare resources in a society such as wealth, income, political power and social status.(51) In this structure racism and economic inequality are institutionalized. The result of this social structural system is that greater deprivations accrue to those who are poor and non-white, in every arena: material, emotional, psychological and of every commodity: health, education, political and economic power and the like.(52-55).

The health care delivery system is no different than all other components of the U.S. social structure in terms of its reaction to race and class. In fact, health care in the U.S., is a multibillion dollar industry that in and of itself is reflective of race/class divisions in the society. Within the hierarchical structure of the industry, a disproportionately small number, if any, of racial/ethnic minorities are found in administrative, policymaking and other powerful positions such as the chief officers and administrators of mainstream medical schools or professional organizations, hospital conglomerates or pharmaceutical and health insurance companies. In addition, racial ethnic minority populations are seriously affected by the financing issues involved in gaining access to care, which has been previously discussed. (Figure 5, Percent people under 65 Years of age without Health Insurance by race/ethnicity)

The problem for the U.S. is that the same racial/ethnic minority populations in the U.S. who have disproportionately higher rates of poverty and lower levels of education and income are much more likely to be found in low income jobs than in high tech, high paying jobs that come with health insurance. These are also the same groups who have a disproportionately worse health status than the mainstream white population. It is important to note that this connection between health status, race/ethnicity and socioeconomic status is not unique to the U.S. This is a global condition that is well documented in the international health care literature. (56-58).

The role of culture

What has been less documented but has recently come to be seen as an important dimension of health service delivery is culture. Several studies document the influence of culture on health seeking behavior and health care utilization. (59-61) For centuries the accepted mainstream cultural standard in the U.S. was perceived to be White-Anglo Saxon Protestant, (WASP). Despite clear demographic shifts there has been a much slower corresponding shift in recognition of these new and different cultures in health care policy. While the mainstream health care system is based on the Western medical model, it is slowly being recognized that alternative forms of healing and health care are also practiced either exclusive of, or in conjunction with western medicine by a variety of people across the U.S. including racial/ethnic minority populations. In fact there now exists concerns about the extent to which racial and ethnic patients of western trained physicians use alternative medicine in conjunction with prescribed medications and moreover to what extent are physicians aware that this is happening since it is unlikely that physicians would ask questions about alternative health practices. It is certainly clear that race/ethnicity, class and minority group status exert influence on access to, and utilization of, health services. However, the design and delivery of health services must also be mindful and respectful of the cultural dimensions of the group for whom services are intended.

2. U.K.

The 1991 Census of Populations for the U.K. provides the following information on the ethnic composition of the population of England and Wales.

Table 1.

Ethnic Group	**Percent**	**Numbers(000s)**
White	94.1	46,938
Black Caribbean	1.0	499
Black African	0.4	210
Black Other	0.4	176
Indian	1.7	830
Pakistani	0.9	455
Bangladeshi	0.3	162
Chinese	0.3	146
Other Asian	0.4	193
Other	0.6	281
Total England & Wales	100	49,890

There are an estimated three million people of minority ethnic origin living in England and Wales (see Figure 6) and n 1995-96 they constituted approximately 6.3% of the total population. (62) In a similar vein as the U.S., migration to Britain during the first half of this century was predominantly European. After 1950, migration into Britain increased from the Indian sub-continent, Africa and the Caribbean. There was also an influx of Asians and Somalis from East Africa and Vietnamese from South East Asia.

The Chief Medical Officer's report *On the State of the Public Health 1991*,(63) and *The Health of the Nation*, (64) both published in 1992, called attention to the specific ethnic differences in health and urged health professionals to be mindful of cultural differences in all aspects of health care. Since then the NHS Ethnic health unit was established in 1994 for the purpose of working with NHS organizations and local communities to ensure quality and accessible health care for minority ethnic groups. (65)

The Health of the Nation publication is actually the government's strategy for improving the health of the nation. That strategy identified five key areas in which substantial improvements can be achieved:

- Coronary heart disease and stroke
- Cancers
- Mental Illness
- HIV/AIDS and sexual health
- Accidents.

In addition, the document also sets national targets, indicates the action needed, and sets the framework for monitoring the improvements by providing baseline data. While there are some problems with this data, it does establish the fact that in the five key areas, there is higher morbidity and mortality for the Blacks and minorities than for the White population. In one of these areas, mental health, it must be noted that African and Caribbean Blacks have higher rates of mental illness than the White population. The Black and minority population in the U.K. especially such groups as the Bangladeshi and Blacks from the African and Caribbean nations tend to be clustered in pockets within the Greater London area. These are areas of high unemployment, economic deprivation and poor housing. The effects of living in these conditions and the psychosocial impact of racism and discrimination are all contributing factors to mental illness.(66)

The role of race/ethnicity, class and minority group status.

At one point in history, the British empire was so vast that it was spread across several continents and time zones. Blauner suggest that to understand group position in a society we must first understand their initial presence in the society or their initial relationship to the dominant group in the society. (67) Today, many of the Black and minority people who have migrated to the U.K. come from former British colonies in Africa, the Indian subcontinent and the Caribbean. These minorities from former colonies have each had different relationships with the U.K. during and after colonization that influence group status or the position of the group in British society today. Much evidence exists that group position in a society in terms of income, employment, level of education and housing conditions, have an impact on health status.(68-69)

It is important to note that the NHS was designed to serve a largely homogeneous white population. As such, services are oftentimes not organized to meet the specific needs of Black and minority ethnic users. (70) In that regard, a major issue for Black and minority ethnic groups in the U.K. is while they can access services it is access to services that are culturally and linguistically incompatible. In addition, there is no denying the importance of social class in the U.K. It is inevitable therefore that it is also part of the health service delivery system. In that regard, it is an important determinant of access to care. This is supported by evidence in variations in the availability and use of heath services. Another aspect that is also important to note, is that while a significant number of physicians in the U.K. are members of Black and ethnic minority groups they function much more in terms of class. As physicians they may share race and ethnicity with patients but not the same social class with all that that implies.

The problem here is actually a dual set of barriers, one set from the institutional perspective and another from the perspective of the Black and Minority patient. The institutionalized effects of class affect access to services in similar ways for both Whites and minority ethnic patients. However, minorities must also deal with the additional obstacles of racism, discrimination, language and communication barriers which are also entrenched characteristics of the health care system as an institution. On the other hand Black and minority ethnic patients also lack information about what services are available, their entitlements or how to use them.

3. The Analysis

Factors such as race, ethnicity, class and culture have now taken on increased relevance for the U.S. and U.K. because of the current diversity of their populations. Certainly black and other minority populations have lived within the U.S. and the U.K. for generations and in the case of some groups, for centuries. Over the course of the last twenty five years however, migration worldwide has essentially been a movement of racial and ethnic minorities toward developed Northern countries, including the U.S./U.K.. In that regard it has been a movement largely of people of color towards predominantly white societies thus creating de facto plural societies all over the world. (71-72) This new migration is remarkable not only because it is racialized but also because in many instances, within various ethnic immigrant groups, women have outnumbered men. These immigrant women, because of the selective process of migration, tend to be young, within the age range of 14-44. These happen to be not only the prime child bearing but also the prime working years. The makeup of this migration is due in large measure to the structure of capital worldwide which has created stable industrial employment at the lowest end of the pay scale in developed countries and at even lower rates of pay in the developing world. These jobs are increasingly filled in developed countries such as the U.S. and U.K. by racial and ethnic minorities both native and foreign born. More often than not, these laborers tend to be immigrant women (73-74) The result has been a concentration of money at the top of these northern societies and a huge inequality of low income at the bottom. These people at the bottom, whether native or foreign born in both countries will have a negative health status compared to the mainstream white population.

Given certain realities as we stand at the dawn of a new millennium: of increasingly multi-racial societies in the U.S. and U.K. as well as the prevailing view that health care utilization is heaviest for women and children, there then has to be concern about the primary care choices and opportunities that exist for racial/ethnic minority populations in both our countries. This concern is important and relevant for all people in general and for vulnerable populations such as racial/ethnic minorities in particular, for several reasons. Many of infectious diseases thought to be conquered decades ago such as Tuberculosis, measles, etc. have recently resurfaced and sometimes in even more virulent and drug resistant forms. Many of the recent outbreaks of once controlled or conquered infectious diseases are preventable, but health services delivery even in a nationwide government sponsored program can be uneven at best, particularly for racial/ethnic minorities for a host of reasons that include such factors as: culture, poverty, race and ethnicity.

It is clear that the U.S. and U.K have begun to address these issues and are committed to improving the health of their racial/ethnic minority populations. However much work lies ahead in that the effort to address the specific health needs of racial and ethnic minorities will require changes in social structures particularly on the part of the mainstream populations and institutions in both countries. These changes will range from the attitudinal to the actual sharing of power in that a major pathway to improving the health of racial and ethnic minorities is to be found in the amount of participation and involvement they will be given in planning and designing the healthcare provided in their communities. From a systems perspective the changes required may very well occur because they appear to be useful in maintaining the stability of the entire social structural system. Because the systems perspective maintains that change rarely comes from within but must be stimulated from outside, then this joint collaboration on this project is indeed important because each country will help to stimulate change for the other, albeit incrementally. On the other hand, although everyone will have to make changes, including racial and ethnic minorities, conflict theory says the "haves" will do so reluctantly if at all, because they want things to stay the way they are. Unless, of course, they determine at some point, that these political and changes will ultimately be in their self interest.

THE POLITICAL ECONOMY OF PRIMARY CARE DEVELOPMENT IN THE U.S AND U.K.

1. U.S.

Despite the conservative penchant in American politics for non-involvement of government in economic affairs, there is government involvement at every level of health care. At the Federal level, government is very involved in Medicare payments for health services for the elderly and government is involved at the Federal and state levels in funding Medicaid. Health care in the U.S. can be a lucrative economic enterprise and as such it tends to be extremely politicized. Further the means by which public monies for health or any other public goods or services are distributed is politics which means that health care approaches and strategies are usually if not always politically and economically motivated. In that regard the lion's share of public and private monies for health care tends to go to the groups that are most highly organized politically with enough power to protect their interests. Racial and ethnic minority groups who are disproportionately poor and less educated, tend to have lower levels of political organization and activism and so are often not well represented in American politics. The result is that in the U.S. some of the approaches used were really justifications for not providing services to racial and ethnic minorities. In addition, some strategies led to an uneven distribution of health care resources to racial and ethnic communities and populations and a dearth of minorities functioning as physicians, or in positions of power in the health industry.

Two opposing but similar strategies have been used over the years in the U.S. with regard to the development of health policy and services for racial and ethnic minorities. In one approach the importance of race is downplayed or negated in the analysis of health deficits of racial/ethnic minorities. (75) In the other approach, the claim is made that Blacks and other minorities experience poor health and premature death because of pathological lifestyle behaviors, otherwise known as the "Blame the Victim" argument.(76)

The economic strategies for providing American Indians and Alaska Natives with health services over the years has been and continues to be problematic. As early as 1836, Indian tribes as sovereign nations signed treaties with the U.S. government that included the provision of medical supplies and physician services and promises of hospital construction for which these tribes relinquished millions of acres of land. (77) Health care for Indians was thus established through The Bureau of Indian Affairs (BIA). Although there were sporadic periods of concern about the poor health conditions of Indians the record of the BIA was shameful at best for the next 90 years. Some relief came through congressional action in 1921 which mandated appropriations for interventions to improve Indian health conditions. (78) Today, the Indian Health Service in the Department of Health and Human Services identifies its service population at 1.3 million even though the 1990 census identified 1.9 million Indians residing in the U.S. The IHS operates on an annual appropriations budget from congress which in 1994 was just under $2 billion. The per capita expenditure for Indians serviced by the IHS system is less than the per capita health expenditure for U.S. citizens.(79).

Politically and economically the strategies used for delivering health services to Blacks are also of serious concern. An important and well known fact is that during slavery Blacks were often sought out and indeed relied on to provide healing services for each other and for the general population, especially in the area of midwifery, and child care. It is well known that black medical schools were established during Reconstruction to train black physicians. Howard University College of Medicine in 1968 was followed by Meharry Medical College in 1876. About 8-9 other black medical schools were subsequently formed most of which have not survived. While blacks would later be accepted into mainstream medical schools the ratio of black physician to black population has never caught up and there has been a consistent decline of Black students in the medical education pipeline. (80). Essentially because of racism the U.S. failed to formulate a plan for the development of Black and minority physicians. Today, many of the racial and ethnic minority physicians are foreign born and Black physicians specifically constitute only 3% of all the doctors in the nation (81)

Historically we know that one of the earliest strategies for the delivery of primary care services for everyone in the U.S. including racial and ethnic minorities was dispensaries. However the AMA organized politically to shut them down because dispensaries represented economic competition. BPHC programs managed to survive politically but they still do not have a large enough budget to service all those in need. Incidentally, their survival was only possible because of a strong political network formed by all the health centers across the nation that in effect functions as the political lobby for the BPHC. (82)

Political decisions made for economic reasons in the last two decades have yet to be fully played out. Between 1981 and 1985 the Federal government transferred a greater share of Medicaid funding to the states which left them with no other alternative but to make changes in Medicaid eligibility rules. The combination of these two actions increased the number of uninsured people and led to curtailment of services available through Medicaid. States have responded with strategies of their own. Many states are developing primary care initiatives to encourage development of CMHC and other BPHC programs. States are also working closer with the BPHC to develop Primary Care Access Plans which will identify and recommend how primary needs within that state can be met by combined Federal/State and local resources.

The most recent strategy for delivering primary care services to everyone is of course through Managed Care which is being implemented on a state by state basis

Despite the existence of several definitions for the terms *managed care* and *managed competition,* their basic structure includes three dimensions:

1. A restructured relationship among physicians, hospitals, and insurance companies in which hospitals and physicians form a provider group, sometimes under a health plan.
2. A free market approach based on three fundamental aspects:
    a. The establishment of networks or cooperatives that will purchase group insurance to pay for basic benefits provided by a health plan
    b. Networks that will use three streams of revenue to purchase group insurance:

        - (1) Employer/employee premiums with perhaps an 80%/20% premium payment mix, respectively
        - (2) Individual premiums
        - (3) Government payment of premiums for the unemployed
    - c. Health plan provider groups that will submit bids, from which networks will select the best price and quality of care in order to award a contract from an insurance company to the health plan; the health plan provider group will then offer health care to their subscribers.

3. Government regulations that will:
    - a. Mandate very employer to provide a basic benefits package for his/her employees
    - b. Require everyone to join a purchasing cooperative, network or health plan
    - c. Pay the premiums for the unemployed
    - d. Mandate each state to set up an independent review board to determine:
        - (1) Basic benefits packages that employers will have to provide
        - (2) Costs of packages and limits on health care spending for different geographical regions within the state.

Medicaid Managed Care

In awarding contracts to health plans, insurance companies set a fixed fee per subscriber per month (capitation), payable to the health plan provider group in advance. For that reason managed care is attractive to the states because through capitation they can develop predictable budgets while also containing Medicaid costs. Therefore, Medicaid managed care allows states to offer health services to low income, underserved populations a significant portion of whom are racial/ethnic populations. To accomplish this almost every state has now applied for the 1115 waiver which gives them broad authority to restructure Medicaid eligibility while restricting provider choice. Medicaid Managed Care and 1115 waivers not withstanding, the basic health care needs of racial/ethnic minorities and indeed of everyone are likely to continue to be unmet because States lack sufficient primary care capacity in terms of a pool of trained family doctors and other resources. Nevertheless, Managed Care and Medicaid managed care offers both challenges and opportunities which we will examine in the analysis section.

2. The U.K.

Politically and economically, the NHS reforms will certainly alter the way the NHS has functioned in the past. This completely centralized health care system, that is fully publicly financed and government managed, provides the majority of health care services delivered to the entire population of the U.K.(83) As such the NHS has been a symbol of egalitarianism and cost-effectiveness. Yet the Health of the Nation white paper clearly explained the need to specifically address the health care needs of Black and ethnic minorities as part of the overall national strategy. (84) Both purchasers and providers are now required to have a strategy in place to address black and minority ethnic health issues which was unheard of prior to the reforms.(85) This requirement is now part of national guidelines processes being put into place along with suggested quality standards for purchasers to include in contracts with providers. (86) In order to empower Black and ethnic minority communities to obtain the kind and quality of care that they need, a paper was commissioned by the Department of Health that will provide some direction to assist in the development of the Black and Minority ethnic voluntary sector in the U.K. (87) The paper offers an wide range of avenues through which: health authorities can include the black ethnic voluntary sector, Black and minority ethnic voluntary organizations can work more closely with local commissioners, and NHS providers and the Department of Health can support and strengthen the work and the capabilities of the Black and Minority ethnic voluntary sector. As the reforms are implemented it will certainly be worthwhile to monitor how the efforts to prioritize and strengthen ways of addressing the specific needs of Black and minority ethnic populations will serve to improve their health status if at all. There is recognition that the process of providing improved services to Black and minority ethnic populations will be assisted by making diversity and cultural proficiency training available to the professionals and staff of the NHS. 88)

Overall, the NHS reforms were targeted at a broader set of political and economic issues. The completely centralized NHS has always allowed government to set limits on the amount of and type of health care provided to the British people which many outsiders have labeled rationing. (89) Tight budgets however, led to waiting lists for certain procedures. The antidote to this situation has always been available through the existence of a private sector and the availability of private medical coverage.(90) Although there has been a recognizable growth in the private sector, it remains more of a supplement than a substitute for the NHS which still enjoys significant public support.

With the establishment of internal markets and wider contractual choices, GPs and other providers will now have to compete for patients. The reforms may indeed serve as the catalyst, despite issues of class, race and other barriers, towards the development of a more consumer oriented NHS. A recent issue of *NAHAT Briefing* included recommendations for GPs on how to: provide better service to the non-English speaking patients, disseminate health education and health promotion information, as well as suggestions of Best Practice examples for delivering services to Black and minority ethnic people.

3. The Analysis: What works/doesn't work and why

The political and economic approaches used in U.S. health care policy and planning for the delivery of services to racial/ethnic minorities have not been very effective. One of the main underlying assumption that has not yet been rejected is that individuals alone, despite the realities of health care financing in the U.S. can control their health destiny. Not enough consideration is given to one's economic capacity to gain access to a decent quality of health services or the availability, accessibility and cultural compatibility of health services.

A major limitation of U.S. health care financing is in the uneven distribution of health care resources. The limited budgets of the IHS forces it to ration cares and as a result not all services are guaranteed. This uneven distribution of resources across Indian country means that one area is receiving a full range of services and another receives little all of which contributes to their continued poor health. The absence of planned development of minority professionals has also hurt minority health. The development of primary care can not be effectively accomplished without an adequate supply of minority physicians. Minority status does not automatically confer cultural competency as there are always issues of class. However, minority physicians would at the very least, have some insider knowledge about members of their groups and would be in a much better position to identify cultural cues and missed opportunities for improving health status among racial and ethnic minorities, as well as for improving the provider performance of their colleagues and institutions.

The best analogy that can be drawn here is that through the women's movement, the issue of gender was placed squarely on the table for open discussion and debate particularly by white women. Subsequently a conscious, deliberate effort was made in the U.S. to increase the number of women (predominantly white, as economically they could afford to pay to go) into medical school and they now constitute about 30% of all medical students. A comparable effort has not been made to recruit capable and competent members of racial and ethnic minorities because of an unwillingness in this country to honestly address issues of race and class

Politically, a new found strength in the U.S. is the growing awareness that culture is a powerful determinant of health seeking behavior. This is beginning to open doors to the possibilities inherent in the practice of alternative medicines and in a budding respect for the health practices of other cultures. Part of this is economically stimulated in that mainstream western medicine has encountered serious threats in the last decade from a strong interest among the American public in natural and folk remedies. Health food stores now have a high volume of business as there is almost a quiet rebellion going on against high tech procedures and a quest for simpler alternative and less drugs with their damaging side effects that oftentimes worse than the disease.

On the surface, increased state responsibility for Medicaid appears to pose some problems for primary care development. However, as states implement Welfare Reforms and the new Temporary Assistance to Needy Families(TANF) law, there is hope in discussions under way at the Federal and State levels to de-link Medicaid from TANF, and to reconfigure new criteria for Medicaid eligibility.

Until Medicaid is restructured states face an uphill struggle for the next few years because of the widening gaps in access for the economically disadvantaged and minority populations who do not now and who after their TANF period ends will not qualify for Medicaid.

Unquestionably, Medicaid Managed Care (MMC) has increased participation of private primary care physicians in providing services to Medicaid recipients. However the problem here is that managed care services are only available to those who have insurance whether public or private and so does not begin to address the needs of the uninsured many of whom are racial and ethnic minorities.

In addition managed care companies, as part of the U. S. social structure, as such they have not yet figured out exactly how to service patients from racial/ethnic minority populations and so are inefficient in delivering culturally competent services to these groups. As a result, in the initial rush by states to enroll all of their Medicaid recipients in managed care, Medicaid managed care enrollment was high. However, many states and the managed care companies are now discovering much to their chagrin not only that Medicaid patients have dis-enrolled from some of the managed care plans but also that they continue the inappropriate use of hospital emergency rooms for routine primary care services. The good news is that a federal panel of experts has recently been appointed to study and advise managed care companies on how best to service racial/ethnic minority populations..

The NHS reforms in the U.K that focus on the development of internal markets along the rapid advance of Medicaid managed care and managed care in general in the U.S. are still being played out. In both instances these different but similar market systems are designed to foster competition among providers and purchasers of care for patients and clients. This may very well present an opportune time in history for racial and ethnic minorities to become involved in designing the kinds of services they require in order to better meet the needs of their communities because the economic incentives are now present for providers to meet the requirements and needs of these once forgotten communities.

Finally, unless both countries are committed to take into account the health needs, concerns and issues of racial and ethnic minority populations who have the poorest health in the nation, efforts to improve the health of the population in general will surely fail In keeping with both systems and conflict theories it seems indicated for everyone from the most powerful to the least that we accept fully accept that the health status of both mainstream populations and racial ethnic minority populations are inextricably intertwined.

Powerful lessons have indeed been learned by both the U.S. and U.K. about what works, what doesn't and why. We now know that we can leave discriminatory approaches and strategies behind, they simply do not work and worse they compromise the health of racial and ethnic minority people. The U.K. must continue its work of establishing quality standards to use in monitoring the delivery of services to Black and minority ethnic populations. In the U.S. we must develop a more egalitarian system for distributing health resources as failure to do so affects the health of racial and ethnic minorities and ultimately the health of everyone. It is a good time in the U.S. to invest in the reconfiguration of eligibility requirements for Medicaid, preferably with greater Federal involvement in order to separate it from TANF and to use it to cover more of the people who are uninsured. Both nations must now work together to establish protocols for such areas as Diversity or cultural proficiency training, as well as a full agenda of collaboration as we move to improve the health of our nations.

C. OPPORTUNITIES FOR COLLABORATION AND RECOMMENDATIONS FOR FUTURE ACTION.

Both the U.S. and U.K. are fully aware that any improvement in the health status of racial and ethnic minorities must flow from a strong research agenda. To deliver effective primary care services to the entire population of both countries including racial and ethnic minority populations, we must first acknowledge two critical factors. Given what we now know about the progressive nature of health deterioration over time and how this is influenced by behavior change, we must recognize that medicine has failed in terms of its ability to help us change behavior. This is not to detract from the amazing life saving technological advancements witnessed in the last fifty years alone.

Therefore, the challenge facing both countries and their health systems, is how best to bring about behavioral change, considering the extent to which health behavior and practices are influenced by culture. In that regard some research questions to be explored are:

- Why do health services fail to reach some racial and ethnic minority populations?
- What institutions and media best relate to these group?
- What interpretations do certain groups give to the existing health care information available to them?
- Given the ability of preventive behaviors to improve health status, how must bio-medicine expand in order to change behavior?

In many ways, the development of primary care as a national health services delivery strategy that will meet the needs of everyone, including racial and ethnic minority populations, demands a new kind of research. One that is population driven.

In order to develop an effective primary care program to service populations that the mainstream system does not really know enough about, research or needs assessment of these communities must be conducted using totally new paradigms.

First the community must be involved from the inception in planning the research. Community members must be trained to serve as point persons in data collection as they are much more likely to obtain data that is accurate than the outside researcher. As data is analyzed, members of the racial/ethnic groups being studies must assist with interpretations of the data or faulty interpretations will result.

This type of research approach will yield several beneficial and ideal results. To begin with education about health promotion and disease prevention will flow in two directions rather than one. Mainstream professionals will be educated by racial/ethnic minority groups members about what their health care needs are which will make planning for service delivery much more focused by creating a specific match between needs and treatment/services. As a community or specific population engages in data collection and research, they gain ownership of the data as well as the results and ultimately of their health care choices and opportunities. In fact several foundations have funded projects in the U.S. using this approach with very positive results (91). The data will be their expression of what their health needs are and what their usual health practices are including alternative health practices and the kinds of health services they are seeking. Community involvement in research about their health issues, empowers that group and enhances their ability to assume greater responsibility for and commitment to their own health status improvement.

In view of the advance of managed care, it seems evident that what ever ways in which primary care development proceeds in either country, services will be delivered within a managed care structure. Therefore the work that lies ahead is how best to integrate existing and developing primary care programs into managed care networks. This is the priority. It is also the difficulty. The U.S. and U.K. must collaborate on studies and planning processes designed to assist this kind of integration that will lead to services capable of serving everyone including racial and ethnic minority populations. Several potential hypotheses await this type of collaborative study

Apart from research, both nations need to immediately collaborate on:

1. the development of a White Paper that offers a broadened definition of health and well being to include a more comprehensive balanced definition for total health. These kinds of definitions

have already been put forward as early as the Alma Ata Conference in 1976. Another comprehensive definition has been advanced by the World Health Organization. Others abound. A joint statement issued by both nations would begin to create commitment internally to the reality of a more comprehensive definition of health for each of the two nations and it will also have international repercussions.

2 Establishment of guidelines that will regulate their respective managed care markets to ascertain that the services of managed care companies are:

- based on primary care characteristics
- function according to a set of "best practices" guidelines that guarantee the provision of: case management services, outreach and education services, and culturally proficient staff and providers.
- for-profit managed care companies provide a certain percentage of care to the uninsured or contribute a percentage of their profits towards care for the uninsured.

3. Design Reforms for medical education to humanize the western bio-medical model without stripping it of its technological capabilities. The goal is have less physicians practice medicine from a purely a bio-medical approach and have a majority of physicians who practice medicine from a bio-psychosocial or some other more inclusive perspective.

3. Establish bi-national programs in which we can cross train professionals and staff of voluntary sector organizations, serving similar communities in their country, on how to conduct outreach and health promotion, disease prevention community education programs and campaigns that are effective with specific populations.

4. Establish bi-national programs for the purpose of reaching into racial and ethnic minority

communities to recruit and train physicians, nurse practitioners and other health professionals from those communities. The conditions they must meet: that they return to serve their communities for a stipulated number of years in exchange for their education. Racial and ethnic minority communities must also be encouraged to propose students who will return to serve them. This would equalize the distribution of medical personnel as a health care and community resources while at the same time begin the process of empowering racial and ethnic minority communities.

5. Mandate/legislate that all physicians from the very established to those currently in school under go physician training that includes the passing exams in cultural proficiency which has less to do with speaking foreign languages and much more to do with respect for the role of culture in health seeking behavior, health care utilization including the practice of various forms of alternative medicine and healing.

OBSTACLES TO EQUALITY
ISSUES FOR PURCHASER AND PROVIDER

The founding fathers of the United States recognized the importance of equality and wrote in the United States Constitution that all men are created equal and have the right to life, liberty, and the pursuit of happiness. Health is an important part of this equation, with equal access to quality health care being the ideal. This paper will look at some of the obstacles to equality in health care and, in particular, issues for both purchasers and providers of health care.

The United Kingdom and the United States share many characteristics, from a common dominant language to ethnic and cultural diversity of their populations. Both the United Kingdom Department of Health and the U. S. Department of Health and Human Services share a deep concern about and face health care issues of the racial and ethnic minority populations in their respective countries. This diversity poses unique challenges to the health care systems and the purchasers and providers in particular in each country. The purchaser must design systems that are flexible enough to adapt to different populations and providers must not only master an infinite amount of medical knowledge but also must be culturally competent in a wide array of cultures so as to effectively communicate and treat patients from these cultures.

The United States Department of Health and Human Services, like other health systems, has two main goals. The first is to optimize the health of the population by applying the most advanced knowledge about disease causation and management of illness to maximize health. The second goal is to minimize the disparities across the population subgroups to ensure equal access to health care and maximize the opportunities to achieve optimal health for everyone. The second commitment was strengthened in 1985 when the Office of Minority Health (OMH) was created in response to a departmental task force report that detailed the continuing disadvantages in health status faced by African Americans, Asian Americans, Pacific Islander Americans, Hispanic/Latinos, and Native Americans. It was further strengthened in 1990 when the Disadvantaged Minority Health Improvement Act (Pubic Law 101-527) was enacted, which provided statutory authority for OMH. The Office of Minority Health is committed to working for and advocating for a clearer focus on prevention, improved services, and more culturally and linguistically competent health care services to minority populations. OMH serves a coordinative role at the Federal level by defining objectives for the Department of Health and Human Services' programs that target minority populations, organizing and planning activities, serving as an information resource or clearinghouse, and providing technical support to state, county, and community health departments, as well as to the public and private sectors in health care.

In 1991 we spent 13% of our Gross National Product on health care — more than $2900 for every person.[1] This is three-quarters as much as we spent on food and housing. Even after adjustment for inflation this represents a 62% increase in the prior decade. As health care expenditures have increased, so has the number of uninsured and under insured. The increased costs have also brought about many changes so that health care in the United States is in tremendous flux. The rapid changes in health care make it difficult to get current data, develop and implement responses to the changes, and provide care to needy populations. In this time of rapid change it is important to protect and improve the quality of care.

BACKGROUND

There have been many studies that have documented that, for minorities in the United States, there is not equal access to health care services, as well as educational, economic, social, vocational, legal, and political services and opportunities. This paper will focus on the health care issues but the other issues certainly play a role in the disparities between mainstream and minority populations' health status.

The racial/ethnic breakdown that will be looked at will be 1) African American (Black); 2) Pacific Islander American; 3) Asian American; 4) Latino/Hispanic; 5) Native American (American Indian and Alaska Native). By the year 2000 the U.S. population is projected to be 270 million people.[23] African Americans will represent 13.1%, Hispanics 11.3%, and other racial groups including American Indian and Alaska Native, Asian American, and Pacific Islander American will be 4.3%.[23] The 1989 National Health Interview Survey (by The National Center for Health Statistics) demonstrated a disproportionate number of minorities were without health care coverage. The Medical Expenditure Panel Survey (April 1997) co-sponsored by The Agency for Health Care Policy and Research (AHCPR) and the National Center for Health Statistics (NCHS) showed that in early 1996, 17% or 44.8 million, people were uninsured. Over 33% of Hispanics and 23% of African Americans were uninsured, compared to less than 14% of other groups (including whites). Hispanics were 11% of the population but 21% of the uninsured. African Americans were 13% of the population but 17% of the uninsured. The 1992 Supplemental Income Programs Participation Survey (U.S. Bureau of the Census) showed that minorities represented a disproportionate number of those in poverty requiring public assistance. A number of studies [13,38] have shown that minority providers are more likely to provide care for minority and under served populations. The Office of the Associate Director for Minority Health at the U.S. Centers for Disease Control and Prevention has tracked health care providers and students and shown that with the exception of Asian Americans they are under represented. This adds to the disparity in access to health by minority populations.

AFRICAN AMERICANS

African Americans are the largest minority group in the United States and in the 1990 census numbered 30 million or 12% of the total U.S. population. The African American population is younger than the non-Hispanic white population. 76.5% of African Americans are under 45 compared to 65.8% for non-Hispanic whites, and the median age for African Americans is 28 compared to 33.9 for non-Hispanic whites.[8] A significant proportion of African Americans live in the south, and most are urban dwellers.

Socioeconomic indicators show African Americans are disproportionately more disadvantaged that whites. African Americans have fewer years of education than whites: for example, 63% completed high school compared to 78% for whites. Only 11% completed college compared to 22% for whites.[8] Poverty is also more common with 32% of African Americans classified as poor, compared to 11% of whites. A higher percentage of African Americans are without telephones, and a higher percentage report they live a sedentary lifestyle,[8] adding to their lower health status.

Culturally, African Americans tend to be more family oriented than the individually oriented whites and are more fatalistic and use alternative health providers more readily. Like other minority communities, there is more distrust of Western medicine and especially government sponsored research. This is in large part due to experiences such as the Tuskegee Experiment, a Federally sponsored and funded study in which a group of African American men were purposefully exposed to syphilis and left untreated for decades while their health status and condition were monitored.[30]

There is a large gap in data on the African American population. The researchers being predominantly white and from outside the community, their lack of knowledge about cultural beliefs and social norms, and the communities' distrust of research perpetuate the scarcity of good data on this group. This is often cited as a reason intervention dollars are not released, thus perpetuating the discrepancy in health. This is often sited for other minority groups as well. Heart disease, stroke, and cancer (lung, breast and colorectal) are the leading causes of death for African Americans. This is the same as it is for whites, but African Americans tend to seek care later, get delayed treatment, and have poorer outcomes than whites.

The church, both Christian and Islamic, plays a large part in the African American community and is an important factor in health beliefs and practices, as well as an important social focal point. Many community based intervention programs have utilized this fact, and realized much more success than they would have if they had not utilized the churches pivotal roles in the community.

The main barriers to health care and risk reduction are language and cultural diversity (with provider and program ignorance), racism, low socioeconomic status, lack of insurance, sedentary lifestyles, and social surroundings that do not promote or reinforce positive health choices.

ASIAN AMERICAN

There are 6.9 million Asian Americans, the largest group being the Chinese, which constitute 2.6% of the U.S. population. They are distributed in every state, but the majority, almost 80%, live in ten states. 55% live in the West, whereas only 21% of the total population lives in the West.[8] It is largely an urban population. The 1990 census tabulated information on 15 different groups of Asian Americans. In this group there are more than 30 languages and dialects, and more than two-thirds of the group speak their native language at home with a large proportion having limited proficiency in

English, making it one of the most diverse groups. Like the other minority groups, it is growing faster than the non-Hispanic white population, but it is largely due to immigration instead of to higher fertility rates. In the 1990 census, 66% of Asian Americans were born in foreign countries.[8]

Socioeconomically, they range from relative affluence to frank poverty. The 1990 census indicated that 14% of Asian Americans lived in poverty compared to 13% of the total U.S. population. The highest rates were in the Hmong (64%), Cambodian (43%), and Laotian (35%).[8] The lowest rates were in the Japanese (7%) and Filipino (6%) populations. Those that have been in the U.S. for a longer period of time tended to have higher socioeconomic indicators. There is also a wide range of educational attainment. 76.1% of Asian Americans completed high school and 37.7% were college graduates, compared to 75% and 20.3% respectively for the general U.S. population. 87.5% of Japanese Americans completed high school but only 31.1% of the Hmong completed high school.[8]

In 1980, the life expectancy for Japanese Americans was 78.8, Chinese Americans 79.7, and Filipino Americans 78.8, compared to 76.4 years for whites.[8] Little is known about the other groups of Asian Americans.

Heart disease, lung cancer, stroke, and breast cancer are the leading causes of premature death, although the rates are consistently lower than for whites. Hypertension, asthma, and diabetes are the leading chronic diseases, but again, rates are lower than for whites. The Behavior Risk Factor Surveillance System indicated higher rates of sedentary lifestyle but lower rates of obesity, smoking, elevated cholesterol, and binge drinking. The data for the smaller ethnic groups is sparse, so it is difficult to make many conclusions about these groups.

Many Asian Americans utilize and follow ancient Eastern philosophies of holistic health and traditional medicine that emphasize preventive elements such as good diets, healthy behaviors, and use of herbs and acupuncture. In general, the longer they have been in the United States the more likely they are to utilize Western medicine.

Ethnic diversity, language barriers, low socioeconomic status, lack of good research data, and lack of utilization of Western medicine are the primary barriers in providing care for this very diverse population. It is tempting to ignore this group since the larger three groups have better statistics than the general population, but there are many groups that have poorer numbers, and without adequate data, interventions cannot be easily made, nor is the chance of success very high. Data collection should include, but not be limited to, a) country of birth; b) year of immigration; c) language; d) education; e) individual income; f) employment status; g) health insurance status; and h) occupation. Much work needs to be done to better understand and manage the health care of this group.

PACIFIC ISLANDER AMERICANS

The 1990 census identified 365,000 Pacific Islanders. The largest group is the Native Hawaiian. The rest come from the U.S. Associated Pacific Islands which consists of three Flag Territories and three freely Associated States. The Flag Territories are more closely associated with the United States and consist of 1) American Samoa; 2) Territory of Guam, and 3) The Commonwealth of the Northern Marianas Islands (CNMI). The three Freely Associated States are self governing and have the freedom to choose full independence. They consist of 1) The Federated States of Micronesia (FSM) composed of four states (Chuuk, Kosrae, Ponape & Yap); 2) The Republic of Palau (also called Belau), and 3) The Republic of The Marshall Islands (RMI). Following World War II, the U.S. asked for and took the responsibility for the health education and welfare of the populations indigenous to these six jurisdictions.

Unfortunately most data sets place this group within Asian statistics, even though there are major differences between these groups. For example, Pacific Islanders are less likely to be college graduates (10.8%) than Asian Americans (37.7%), compared to 20.3% in the general population.[8] 16% of Pacific Islanders are foreign born compared to 66% in the Asian American population. The quality of what little data there is has come into question primarily because of small sample sizes. The majority of data that exists is on Native Hawaiians who reside on the seven islands of the State of Hawaii. Most of the data on this group is from the State of Hawaii Health Surveillance Program. Comparing Native Hawaiians to the general U.S. population, the overall age and gender specific death rate was 34% higher. Heart disease was 44% higher, cancer 39% higher, cerebrovascular disease 31% higher, and diabetes mellitus 22% higher. When comparing full-blooded Native Hawaiians (100% Native Hawaiian ancestry) to the U.S. general population, the death rate was 146% higher. Contrasting full-blooded Hawaiians with the five leading causes of death in the general U.S. population, death rates were 177% higher for heart disease, 126% higher for cancer, 145% higher for cerebrovascular disease, and 588% higher for diabetes mellitus.[2] Lifestyle changes have brought about these changes in a previously healthy, vigorous population.[26]

Native Hawaiians have the lowest educational attainment, lowest personal income, and lowest life expectancy of any racial group in Hawaii.[18] They also have the lowest rate of early prenatal care, highest birth rate, and highest infant mortality of any other racial group in Hawaii.[18] Late prenatal care has been felt to be due to lack of trust in Western medicine, inadequate access to care, low socioeconomic status, and poor health habits including nutrition. Native Hawaiians lack a U.S. Governmental treaty (like American Indians and Alaska Natives have) or proclamation (like other Pacific Islanders have) to have their health care, education, and welfare provided for.

The remaining Pacific Islanders exist in a third world environment, with isolation and long distances to health care, inadequate health care, high rates of infectious disease (acute respiratory infections, malaria, diarrheal diseases, conjunctivitis, and yaws), poor sanitation, and high infant mortality. As more Western lifestyles have been adapted (sedentary with increased fat, tobacco, & alcohol consumption), heart disease, cancers, and diabetes have become the leading causes of death in most countries.[47] This group suffers from a lack of awareness of their health care needs, geographic isolation, and lack of financial resources necessary to provide adequate care. Like American Indians and Alaska Natives, their health care only is provided in their own homeland, i.e. if they move to another state or territory, they lose their health care benefits.

These small but diverse groups have many barriers to health care, but lack of awareness of needs, poor access to care, inadequate cultural insensitivity, lack of good research data, and insufficient education, especially health education, are but a few things that contribute to their inferior health status compared to other groups.

HISPANIC/LATINO AMERICANS

This group is the second largest and fastest growing minority group in the United States. This is due to both high immigration and birth rates. In the 1990 census, there were 22.4 million Hispanic/Latinos, an increase of 53% over the last decade. This rate is more than five times that of the total U.S. population. The largest group was Mexican American which accounted for 61% of this diverse group. There are over thirty groups in this minority population which includes all races whose ancestry can be traced to Spain, Mexico, Puerto Rico, Cuba, or to any of the Spanish-speaking Latin American countries. In the 1990 census, 91.3% were white, 5.4% African American, 2.1% Asian or Pacific Islander, and 1.2% American Indian or Alaska Native.[8]

It is a young population with 82% being less than 45 years of age, compared to 66% in the non-Hispanic white population. 36% were born in foreign countries, and immigration status greatly influences health status.[8] They are distributed throughout the country, but the largest concentrations are in the Southwestern United States.

Educational attainment is lower for Hispanic/Latinos than non-Hispanic/Latinos. Of Latinos age 25 and older, little more than half completed a high school education, compared to 80% in the non-Latino population. 9% have a college education or higher compared to nearly 23% among the non-Latino population.[33]

In 1993 unemployment rates were 11.9% for Latinos compared to 7.1% for non-Latinos and were highest among Puerto Ricans (14.45) and lowest for Cubans (7.3%)[32] In 1992 29.3% of Latino households lived below the poverty level, more than twice the rate for non-Latino households (13.1%). Hispanic/Latinos had the highest rate of uninsured (33%) according to the 1989 current population survey, compared to 13% for non-Hispanic whites.[42]

Many Latinos believe health is a state of balance in the body and disease is a state of unbalance. The hot-cold theory of disease is an example of how medical treatment can restore balance. “Hot” illnesses are treated with cold liquids and “cold” illnesses with hot liquids. Many will utilize traditional healers (Curanderos) before seeking Western medical care. There is often a fatalistic attitude about getting cancer, heart disease, diabetes, or other diseases, which can lead to a delay in seeking Western medical treatment.

Language can often be an impediment to getting adequate medical care. Almost 78% of Latinos speak Spanish at home, and only half could speak English very well. Many medical facilities, especially in areas with lower concentrations of Hispanic/Latinos, do not have bilingual medical providers. This can cause a delay in seeking care, and inadequate care or mistakes are more likely if there is not medical staff competent in Spanish. Even utilizing non-medical interpreters can lead to mis-communication.

Even though there is a lot of data on this diverse group, there are many gaps. The Hispanic Health and Nutrition Examination Survey (HHANES) looked at three groups: Mexican Americans in the South Western U.S.; Puerto Ricans in New York City; and Cubans in Florida. It went a long way in filling the void, but data on all the other subgroups and populations from many more parts of the country is needed. The leading causes of death in Latinos are: 1) cardiovascular disease; 2) cancer; 3) accidents; 4) cerebrovascular disease; 5) homicide; 6) liver disease and cirrhosis; 7) pneumonia and influenza; 8) diabetes mellitus; 9) HIV; and 10) perinatal events.[9]

Besides lack of adequate data, language, culture, poor health habits, socioeconomic status, and insurance status all contribute to this significant portion of the population not receiving adequate health care.

NATIVE AMERICAN (AMERICAN INDIAN & ALASKA NATIVE)

Although Native Americans are the original inhabitants of America, they are the smallest and most diverse of the minority populations. There are over 550 distinct and federally recognized tribes [14] or nations and over 200 separate languages.[33] Each Nation has its own traditions, heritage, and culture. The term Native American refers to American Indians and Alaska Natives. Alaska has three distinct racial aboriginals. They are American Indian (Athebascan, Tlingit, Haida, and Tsimpsian nations), Aleut, and Eskimo. Native Hawaiians are technically Native American but are placed in the Pacific Islander group as they do not have a special trust (Article I, Section 8 of the U.S. Constitution) relationship with the Federal government. They, therefore, are not a sovereign nation as the American Indian and Alaska Natives are. They do have similar health problems, and there are many cultural similarities.

There are nearly 2 million Native Americans spread throughout the U.S., but predominantly in the West. They are a young population with a median age of 26, compared to 33 for the general population. There is lower educational attainment with 65.5% graduating from high school (compared to 75.2% for the U.S. general population) and 9.4% graduating from college (compared to 20.3% for U.S. population as a whole). They have a lower socioeconomic status with 31.2% living below the poverty level compared to 13.1% for U.S. all races.[8]

The Indian Health Service, an agency of the U.S. Public Health Service, provides care for nearly 60% of the Native American population. Indian Health care was initially in the Department of War. In 1955 the Indian Health Service was formed within the Public Health Service in the Department of Health and Human Services. It has gone through many changes. Initially the leading causes of death were infectious diseases. Currently the leading causes of death are heart disease, cancer, accidents, diabetes mellitus, and liver disease/cirrhosis. This agency is chronically underfunded and understaffed. In 1996, the per capita funding for health care was $3046 and the Indian Health Service average was $1200[14] according to the Indian Health Service Office of Planning, Evaluation and Legislation. According to the Indian Health Service Diabetes Care for fiscal year 1996, only 29% of diabetics had received dietary counseling by a registered dietitian.[28] This illustrates how preventive services are not adequate when funding is tight. The IHS does provide care for about 60% of the Native American population and is mainly on Native trust lands (reservations). There are a few urban Indian clinics but most Native people who leave their lands are uninsured or covered by Medicare/Medicaid or other health insurance. They must return to the reservation to access the Indian Health Service.

In response to this under-funding, many tribes have opted to take over patient care services (contracting) or take over all the funding (compacting). The Tribes feel they can better utilize the funding as they know the specific needs of their own people. It is too early to tell if this will have a significant impact or not.

Both reservation and urban Natives utilize traditional healers. Health is not seen as the absence of disease but as harmony or balance with oneself (mind, body and spirit), harmony with others, and harmony with ones surroundings or environment. Disease or illness occurs when harmony is broken. The traditional healers treat the cause (heal from the inside), while Western physicians treat the symptoms (heal from the outside). There are many differences between Native and mainstream cultures and many differences between tribes. It is important to keep this in mind when working with these populations.

The leading cause of death is heart disease followed by cancer, accidents, diabetes mellitus, and chronic liver disease and cirrhosis. Many of these problems are made more difficult to treat since a significant number of this population lives in remote settings and health care services are far away.

Sedentary lifestyles, unhealthy behaviors, inadequate funding for the Indian Health Service, tremendous diversity, geographic barriers, and poor socioeconomic status are important barriers to overcome for this group to reach the health status of the rest of the country.

PAST STRATEGIES

Numerous attempts have been made to bridge the gap between minority and majority health status. Most have had some impact, but much more needs to be done. Here are a few examples:

PUBLIC

Safety net programs provide care for the uninsured and under-insured. Medicaid, a joint Federal and State program administered by the Health Care Financing Administration (HCFA) and jointly funded by the States and HCFA, provides care for those below or near the poverty level. It especially tries to fund prenatal care and care for children. It provides outpatient care and inpatient care and covers many medications. Providers are forced to take a lower fee (usually 50% of the usual and customary service fee).

The Women, Infants and Children (WIC) Program provides nutrition and health screening, nutrition counseling, and vouchers for high nutrient foods for pregnant women and for children up to five years of age.

Many counties, burroughs, and municipalities provide public health facilities for the poor and uninsured. This is more common in the large urban centers where there is a significant number of poor, which are in large part minority.

There are a number of charitable non-profit organizations that provide care for free or low cost. One example is the Shriners, a charitable organization that raises funds to operate children's hospitals around the country.

As minorities are more likely to provide care for the poor and minority populations and be more culturally sensitive, a number of programs have tried to increase the number of minorities going into health professions. The Health Careers Opportunity Program (HCOP) provided funds to academic institutions and minority organizations to encourage young minorities to go into the health profession. High school and junior high students were brought in for workshops and summer programs that showed them what opportunities existed, gave them strategies and skills to help them succeed, and mentored them with minority health professionals. Many universities and health profession schools ran similar programs with their own funds.

Colleges and universities gave preference (affirmative action) to qualified minority applicants in an effort to bridge the gap between minority and majority health professionals. Affirmative action has come under intense criticism in the current conservative political climate, and schools can no longer openly select students by race. While it was in operation, affirmative action went a long way in increasing the number of minority health professionals. Many fear that without it, ground will be lost.

The National Institutes of Health has many programs that encourage minorities to go into research and academic careers. The National Heart, Lung and Blood Institute (NHLBI), the National Cancer Institute (NCI), and The Office of Research and Minority Health (ORMH) have lead the way in promoting research careers to minority students.

The number of physicians in the U.S. is felt to be adequate, but the geographic distribution and the specialty mix has been less than ideal. The National Health Service Corp placed primary care physicians in under-served areas in payback for funding their medical education. The program had many problems and, in tight financial times and a conservative political climate, it suffered severe cutbacks.

Cultural competency of health professionals is a must when working with minority populations. Many medical schools and residency training programs have cross cultural training as part of their curriculum, but it is not universal and often not comprehensive enough to be highly effective.

Despite lots of money, good intentions, and many dedicated people, not near enough headway has been made and much needs to be done. Things are changing rapidly in health care with decentralization and reorganization of government, Medicaid reform, marked increases in prepaid health insurance plans (Health Maintenance Organizations), and more of an emphasis on primary care rather than specialty care. It will take an organized effort and national will to make the necessary changes happen.

The Robert Wood Johnson Foundation's Center for Health Economics Research noted that only a few access-to-care indicators have improved:[1]

1) Neonatal mortality has improved, but primarily for whites.

2) Poor children, especially preschoolers, visit a physician more compared to a decade ago, but the children of the near poor are worse.

3) Measles immunizations are up, but DPT is unchanged and polio immunization is worse.

4) Breast cancer screening is increased, so there is less metastatic disease at diagnosis, but it is not better for black or poor women.

5) There has been an increase in participation of OB/GYN specialists in Medicaid programs.

Despite these small gains, the majority of access-to-care indicators that were examined showed no change or a worsening for the five areas evaluated (family planning, prenatal care, child health, adult health, and dental health). It was noted that money went for expensive high-tech services (specialty care) rather than for low cost screening and preventative services (primary care). The United States Health Care System has failed to provide adequate primary care to our own people, especially the poor, which has a disproportionate number of minorities.

COMPARISON WITH THE U.K.

My interest in the differences between the U.K. and the U.S. health care systems started in 1989. I was covering the emergency room, and an English gentleman, who was in his late 60's, had come in with chest pain and extremely low blood pressure. He had spent the previous night in a hospital in British Columbia, Canada, being worked up for chest pain, but he was told it was not his heart. His wife, fortunately, insisted that they be given sublingual Nitroglycerin to take with them. He had been having some chest pains off and on for some time. About thirty miles from our facility, he grabbed his chest and slumped over in the car. His wife was driving, but she put one of the Nitroglycerins under his tongue and drove to the nearest ambulance. They brought him to our facility where we gave him a thrombolytic agent and helicoptered him to Spokane, Washington, where he had an emergency bypass surgery. He had severe four vessel coronary artery disease and would not have survived without revascularization. He and his wife were both very grateful for the great care that he had received, albeit expensive, and were very adamant that he would not have survived this episode if it had happened in the U.K.

In 1995, I was the United States Public Health Service Primary Care Policy Fellow. While serving in this capacity, I met a Policy Adviser for the Royal College of Nursing in London. I was to meet with him prior to the U.K. conference. The day we were flying to London, he was involved in a motorcycle accident. Instead of meeting him at the airport, I had to pick him up at the hospital. He had fractured ribs, a leg fracture, and a grade III concussion. When I went to pick him up, I was appalled by the condition of the outside of the hospital. He did not have a CT scan, despite having a grade III concussion and a difference in the size of his pupils which persisted for several days. He did, however, receive free medical care, including his medications. Another acquaintance had been involved in a motorcycle accident in the U.K. Being of minority background, he was placed in a charity ward and was given minimal care. His adoptive parents were of nonminority background. After they had been contacted and came to visit him, his care was quickly upgraded.

I think the timing of the U.K. conference, Health Gain for Black and Minority Ethnic Communities: International Conference Between the U.K. and the U.S., was excellent. It is on the verge of the 50th anniversary of the National Health Service. The NHS is a good system but is drastically underfunded. 5.4% of the GNP was okay fifty years ago, but the system has not kept up with the increasing costs of technology and medicine. It does have universal access that covers the basic care needs for everyone. It has a primary care (general or family practice) focus that is more cost-effective than the speciality care focus seen in the U.S. It has centralization of care, so there is less duplication of services, and administrative costs are less. Its main negative is its lack of funding. There are long waits for specialty services and procedures. While in the U.K., one surgeon told the Health Authority to cancel those below a certain point on the list, as it was unrealistic that they would receive their care with the current funding. Racism is still prevalent. There are a surprising number of minorities in the U.K. The National Health Services Ethnic Health Unit Report, “Ethnicity and Health in England,”[16] estimated it at six percent of the population or about three million. They are primarily an urban population. There are not only complaints of racism, but it is also uncommon to see providers who are culturally competent. There has been no effort to fund programs that would encourage resident minority young people to seek medical careers. Even though the NHS is now fifty years old, it was not until 1993 that a report was generated — “Ethnicity and Health: A Guide for the NHS”. It was not until 1994 that the NHS Ethnic Health Unit was formed. These are steps in the right direction, but they come quite late in the history of the NHS.

In evaluating the U.S. system, it fares no better, and although there are similar shortcomings, it fails in different areas as well. There is generally rapid access to high-tech speciality care. The down side is that this is a very expensive approach. Although primary care has made some gains, it is still not in a strong enough position to significantly lower health care costs. President Clinton's failed effort to achieve universal access to health care did prove how strong the health insurance and specialist provider lobby was. The specialty approach and large number of health plans causes fragmentation of health care, duplication of services, and tons of paperwork. As in the U.K., cultural competence is low. There are, however, great programs at The National Institutes of Health, The Centers for Disease Control and Prevention, and at many medical schools, universities, and teaching hospitals that train minority providers and researchers. They are already culturally competent, and research has shown that they are much more likely to care for under-served populations.[13,38,43]

As a primary health care provider practicing in a rural setting, it would be nice to see universal access to health care become a reality in the U.S. As an American Indian who would not have made it through all the obstacles without Affirmative Action, it would be nice to see it remain in place.

The Conference was the first step in allowing our systems to learn from each other. Hopefully this endeavor will continue long into the future.

RECOMMENDATIONS

Many groups have made many recommendations. Most indicate a greater need for more primary care providers and fewer specialists. They also recommend more providers from under-served populations and more cultural sensitivity in medical training and providers. They have many good ideas on how to improve the health system in the United States. Here are a few -- a description of the group will be followed by their recommendations:

In 1984, then Secretary of the Department of Health and Human Services, Margaret M. Heckler, appointed Dr. Thomas E. Malone, Deputy Director of the National Institutes of Health, Chairperson and selected 18 senior scientists and officials to be on a task force on black and minority health. They came up with the following recommendations: [46]

> RECOMMENDATION 1: AN OUTREACH CAMPAIGN. The Department of Health and Human Services should launch an outreach campaign to disseminate health information and education materials and program strategies specifically designed for minority sectors of the population, including Blacks, Hispanics, Asian/Pacific Islanders and Native Americans. The campaign should strengthen and expand present departmental health promotion efforts emphasizing

preventive aspects of those public health areas identified by the Task Force which have the greatest impact on death and disability among minority populations: cancer; cardiovascular disease; chemical dependency; diabetes; homicide, suicide and unintentional injuries; and infant mortality.

RECOMMENDATION 2: PATIENT EDUCATION. The Department of Health and Human Services should ensure that its materials, programs, and technical assistance for patient education are responsive to minority population needs, especially those provided in specific health care service settings, such as medical, community based, schools and worksite locations. Emphasis should be given to those public health topics that have the greatest impact on death and disability in minority populations. Concomitantly, attention should be given by the nation's schools and universities to training health care providers and educators to be sensitive to minority cultural and language needs.

RECOMMENDATION 3: DELIVERY AND FINANCING OF HEALTH SERVICES. The Department of Health and Human Services should continue to investigate, develop, and implement innovative models for delivery and financing of health services, based on current departmental authorizations. The major objectives of the models should be to increase flexibility of health care delivery, facilitate access to services by minority populations, improve efficacy of service and payment systems, and modify services to be more culturally acceptable.

RECOMMENDATION 4: DEVELOPING STRATEGIES OUTSIDE THE FEDERAL SECTOR. The Department of Health and Human Services should initiate discussions with minority and non-minority health professional organizations, academic institutions, state governments and health departments, and other entities from the public and private sectors to develop strategies to improve the availability and accessability of health professionals to minority communities.

RECOMMENDATION 5: DEVELOPING STRATEGIES WITHIN THE FEDERAL SECTOR. The Department of Health and Human Services should conduct both intra- and interdepartmental reviews to identify and provide for collaboration between the various activities currently being supported within the Department and other elements of the Executive Branch, respectively. The reviews should focus on programs that have impact on the actual or potential availability of health professionals to minority communities.

RECOMMENDATION 6: BUILD THE CAPACITY OF THE NON-FEDERAL SECTOR TO ADDRESS MINORITY HEALTH PROBLEMS. The Department of Health and Human Services (DHHS) should increase its involvement with State, local and community agencies and organizations to encourage efforts specifically oriented toward meeting minority health needs. Recognizing that communities have unique insights into their own health problems, DHHS should undertake activities to increase awareness by minority communities of the Federal ability to provide an overview of health problems and to provide technical assistance through departmental efforts in assisting communities to define local health goals, objectives and priorities, develop strategies for resolving health problems, and set action plans into operation. Localities can build an internal capacity for meeting the health needs of local minority populations.

RECOMMENDATION 7: IMPROVING AND FULLY USING AVAILABLE SOURCES OF DATA. DHHS should undertake activities which would improve existing sources of health data, such as enhancing cooperative efforts with the States in recording vital statistics, incorporating specific racial/ethnic identifiers in data bases, and over sampling selected minorities in national surveys. Furthermore, DHHS should support innovative uses of currently available data consistent with the Privacy Act and confidentiality constraints. Analysis such as cross-comparisons from different data sets and specialized studies should be encouraged because they can contribute to understanding the health status and needs of minority populations.

RECOMMENDATION 8: RESEARCH AGENDA. DHHS should adopt and foster a research agenda to investigate factors affecting minority health and should incorporate appropriate research activities on minority health into ongoing research programs consistent with the referral guidelines of each DHHS agency.

The Task Force considers the following areas to be of major importance for research:

Risk factor identification
Risk factor prevalence
Health education interventions
Preventive services interventions
Treatment services
Sociocultural factors and health outcomes

A report on primary care physician supply and the medically under-served, written by a number of experts in the Health Resources and Services Administration in 1991, had the following recommendations designed to address the eroding primary care education infrastructure and to produce an adequate supply of primary care physicians to practice in the most severely under-served areas: [43]

RECOMMENDATION 1: Use the National Health Service Corp (NHSC) scholarship and loan repayment programs for the under-served areas that are hardest to staff.

RECOMMENDATION 2: Build postgraduate training and services linkages (between training sites and community service sites).

RECOMMENDATION 3: Redirect admissions criteria to students who are more likely to choose primary care careers and serve the under-served.

RECOMMENDATION 4: Promote required third-year undergraduate medical clerkships in primary care.

RECOMMENDATION 5: Promote primary care research.

RECOMMENDATION 6: Train and develop community-based faculty in medical training schools.

RECOMMENDATION 7: Establish graduate medical education financing initiatives for primary care training. Toward this end, Medicare reimbursement funds should 1) reward institutions that expand opportunities for primary care training, especially in community settings; 2) provide individual incentives for medical school graduates to select careers in primary care; and 3) support research and demonstration initiatives in primary care training.

In 1993 the Joint Center for Political and Economic Studies hosted a roundtable on Access to Primary Care for Under-served Americans. It was funded by Aetna Life and Casualty Company and was designed to identify for policymakers the principles behind practical models that can improve access to primary care for under-served Americans. They had several suggestions on how the current system could be modified to improve access for the medically under-served.[32]

RECOMMENDATION 1: Restructure the way graduate medical education for the health professions is funded to provide greater incentives for physicians and other medical professionals to select primary care. One way to do this would be to provide capital grants to subsidize new physicians to establish primary care practices.

RECOMMENDATION 2: Train health professionals to work in teams and encourage the establishment of group practices. Make more frequent and more appropriate use of physician extenders.

RECOMMENDATION 3: Locate medical facilities in areas of greatest need, i.e. near the greatest number of medically under-served persons.

RECOMMENDATION 4: Support the existing public or “safety net hospitals”, health centers, and other publically funded clinics to enable them to provide quality care to the medically under-served.

RECOMMENDATION 5: Establish a health care delivery system with multiple points of entry, e.g. neighborhood clinics, schools, and churches, as well as hospitals and offices of medical professionals - but with limited friction, and encourage as many people as possible to use it.

RECOMMENDATION 6: Establish and maintain a database on the quality of care and the interventions that are most effective (quickest healing with fewest lapses) with the medically under-served.

RECOMMENDATION 7: Provide a health history card and health insurance card for every resident of the U.S. and make both of the cards usable to receive services at facilities throughout the U.S.

RECOMMENDATION 8: Provide comprehensive care, i.e. care that addresses all the health-related needs of the individual and is responsive to the whole person.

RECOMMENDATION 9: Make medical care available to all residents in each cachment or service area, regardless of ability to pay.

RECOMMENDATION 10: Use a sliding scale of fees for health services.

The PEW Health Professions Commission has a mission to help workforce policy makers and educational institutions to produce health care workers who meet the changing needs of the American health care system. In their third report titled *Critical Challenges: Revitalizing the Health Professions for the Twenty-First Century* (1995) they made the following recommendations that are designed to restructure the health professions to meet the demands and needs of the people they are obligated to serve.[11]

RECOMMENDATION 1: All health professional schools must enlarge the scientific basis of their educational programs to include the psycho-social, behavioral sciences, and population and health management sciences in an evidence-based approach to clinical work.

RECOMMENDATION 2: While legitimate areas of specialized study should remain the domain of individual professional training programs, key areas of pre-clinical and clinical training must be integrated as a whole, across professional communities, through increased sharing of clinical training resources, more cross-teaching, more exploration of the various roles played by professionals, and the active modeling of effective team integration in the delivery of efficient, high-quality care.

RECOMMENDATION 3: The next generation of health professionals must be prepared to practice in more intensively managed and integrated systems.

RECOMMENDATION 4: There is a substantial body of literature which concludes that culturally sensitive care is good care. This means two things for all health professional schools. First, they must continue their commitment to ensure that the students they train represent the rich ethnic diversity of our society. Important investments and many successes have been achieved, but this is an obligation that must be continued at each institution until it is no longer an issue. Second, diversifying the entering class is not sufficient to ensure understanding and appreciation of diversity. Cultural sensitivity must be a part of the educational experience that touches the life of every student.

RECOMMENDATION 5: Every professional school must be willing to develop partnerships and alliances that have not been a part of education in the past — partnerships with managed care for training, clinical research, and tertiary care referrals; with computer and software companies to develop information and communication systems to support health services research; and partnerships with State government to determine the best ways to meet the health needs of the public.

RECOMMENDATION 6: All health professions must recognize that the current health professions regulatory system needs to change. Health professionals must work with State legislators and regulators to ensure that regulation is standardized where appropriate, accountable to the public; flexible to support optimal access to a competent work force; and effective and efficient in protecting and promoting the public's health, safety, and welfare.

RECOMMENDATION 7: More training of physicians at the undergraduate and graduate levels into community, ambulatory, and managed-care based settings for a minimum of 25% of their clinical experience.

RECOMMENDATION 8: Create a public-private payment pool for funding health professions education that is tied to all insurance premiums and is designed to achieve policy goals serving the public's health.

RECOMMENDATION 9: Establish an enlarged National Health Service Corp to attract graduate physicians into service roles currently being met by the excessive number of residency positions. (In the U.S. there are many more graduate training, i.e. residency, positions than medical school graduates.)

CONCLUSION

The former Secretary of Health and Human Services, Louis Sullivan, recently indicated that "there is clear demonstrable, undeniable evidence of discrimination and racism in our health care system".[55] Racism encompasses prejudice, negative attitudes and beliefs about other groups. Discrimination is the differential treatment of people based on their race or ethnicity and is viewed as occurring at both the level of the individual and the level of institutions within society. At the institutional and individual levels, racism can determine both the quantity and quality of medical care. There is undeniable evidence that racism occurs from data on insurance coverage to medical treatment outcomes.

What makes addressing this racial discrepancy in health care difficult is the tight Federal budgetary constraints currently affecting our country and the fact that this country truly does not value the poor and disenfranchised.

Many ideas to address access to care issues have been brought forth. Improving data, increasing the percentage of the physician workforce who are primary care providers, and increasing the number of minority providers and researchers are a few that consistently are brought forward.

Over a century ago, Sir William Osler had several profound statements that still are very relevant to the practice and provision of health care today. He said, “The failure to recognize that the results of specialized observation are at best only partial truths, which require to be corrected with facts obtained by wider study....No more dangerous members of our profession exist than those born into it, so to speak, as specialists.” [44] He also said, “It is more important to know what kind of patient has the disease, than what kind of disease the patient has”.[14]

As a nation, we must improve access to culturally competent primary care while controlling runaway costs in order to improve the health care to our nation’s most vulnerable people. This will take strong moral leadership and a national will that at this time does not appear to exist.

We can learn a lot from the U.K. health system. Although grossly underfunded, it has the basics in place, i.e. care focus and universal access to care. It, too, suffers from lack of cultural competency and racism, but training can go a long way to alleviate that problem. Funding programs to train health care providers and personnel costs money but will improve the quality of care for minorities as well as nonminorities because it teaches respect for the individuality of each patient regardless of race.

The U.S. system is specialty oriented and costly, and despite the high cost of health care, there is not universal access. There is excellent funding for training of minorities at The National Institutes of Health, The Centers for Disease Control and Prevention and at most universities, medical schools, and training hospitals. Cultural competency training is also badly needed in the U.S.

I believe the ideal system would have universal access for basic health care with a primary care focus and would be funded somewhere between the U.K. and U.S. health expenditures. High tech, expensive, experimental care would be limited severely to lower costs, and funding for training of primary care providers would be increased. Cultural sensitivity training would be mandatory, and funding for minority students, who are more likely to go to under served populations, would be increased. Research would have a more practical primary care approach that would have a better chance of having a positive impact on the health of our nation now. Currently, most research at NIH, our largest research funder, is mostly in the basic, not applied, sciences and is very esoteric. The recommendations by various organizations are surprisingly similar despite the wide variety of the organizations and their focus and the wide time line between the recommendations.

I would hope continued collaboration between the U.K. and the U.S. health systems would occur. This meeting was a great step, but it needs to be a foundation for continued work to learn from each other's mistakes and successes. Annual or biannual meetings, alternating the host country, would be very helpful. Involving more legislative personnel as speakers and attendees would also educate our governments on these important issues so that they can make more informed decisions, thus improving the health care in our countries.

Respectfully submitted,

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F.A.A.F.P.

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INFORMAL CARE AND THE EMPOWERMENT OF MINORITY COMMUNITIES: COMPARISONS BETWEEN THE U.S.A. and the UNITED KINGDOM

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Abstract

This paper examines informal care and the empowerment of minority communities with respect to health care and health promotion in the United States of America (U.S.A.) and the United Kingdom (U.K.) based upon work prepared for the workshop, "Involving Black and Minority Ethnic users in Delivery of Services and Empowering Communities" presented during the bi-national 1997 U.S.A./U.K. Conference, ***"Health Gain for Black and Minority Ethnic Communities"*** and the information gained from that Conference. "Informal care" is operationally defined as "the practice of alleviating distressful physiological and psychological dysfunctions through all others (e.g., traditional healers, family members, self, etc.) using measures that do not require a physician's prescription or intervention (e.g., lifestyle modifications) typically outside of formal, institutionally based care mechanisms (e.g., homes and communities). Informal care is a significant force in health maintenance, health promotion, and disease prevention. In the U.S.A., at least one-third of the population is estimated to engage in unconventional medical practices, and perhaps, one-half of racial/ethnic populations use informal care. An enormous potential exists to better utilize informal care because informal care is culturally more compatible, relatively low cost, and flexible. The policy of the Indian Health Service in accepting the use of traditional medicine was cited. The U.S. Congress recognized the potential of alternative medicine by establishing such an Office within the National Institutes of Health.

"Empowerment of racial/ethnic minority communities is the right for minority populations to determine their own destinies. In the U.S.A., racial/ethnic minority populations are Blacks, Hispanics, Asians or Pacific Islanders, and American Indian/Alaska Native. These classifications are based upon self-report; in the U.K., the black and minority classifications are based upon countries of birth rather than self-reported racial/ethnic identities. Empowerment of these communities is important both demographically and historically. In demographic terms, racial/ethnic minority populations are increasing at higher rates than the majority population in the U.S.A. and hence, the health status of minorities will become the health status of the nation in the next half century. Historically, racial/ethnic minorities have not been empowered. As a consequence of the 1985 *Secretary's Task Force Report on Black and Minority Health,* Federal measures to address disparities in the health status of minorities were initiated. In March 1994, the U.K. Government initiated the Ethnic Health Unit within the National Health Service. These measures are not mature enough to evaluate their impact. However, progress in implementing measures to empower minorities in the U.K. have begun and are illustrated by the work reported by Dr. Pui-Ling Li, the U.K. counterpart to the workshop, "Involving black and minority ethnic users in delivery of services and empowering communities". Recommendations are made to increase use of informal care and the empowerment for racial/ethnic minority communities and to build upon the works

in progress in both the U.S.A. and the U.K.

PREAMBLE

At first glance, “*informal care*” and the “*empowerment of minority communities*”[y1] communities feel most comfortable in meeting health needs and aspirations. Effective coping for these minority communities (or populations) is empowering. (“Populations” is a term that is used interchangeably with the term, “communities”.) Hence, this paper first delves into an individual discussion of “informal care” and “empowerment of minority communities” and then brings these two topics together.

I. BACKGROUND

A. Definitions. In this paper, *“informal care*” is operationally the opposite of *“formal care*”. “Formal care” is the practice of alleviating distressful physiological and psychological dysfunctions by Western trained allopathic and osteopathic medical practitioners and their affiliated health professionals, e.g., nurses, and professionally certified occupational and physical therapists through institutionally based services, e.g., hospitals, clinics, managed care systems, etc. In the U.S.A., formal care is provided through a variety of health care practitioners typically on a “fee-for-service” basis or through public funding (e.g., Medicaid, Medicare, public health departments). In the U.K., formal care is typically provided without cost to patients through its publicly funded (or statutory care) through the National Health Service (NHS) (Ham, 1996/97). Hence, access to formal care in the U.K. does not include financial barriers that may face populations in the U.S.

By contrast, “informal care” is the practice of alleviating distressful physiological and psychological dysfunctions through all others (e.g., traditional healers, family members, self, etc.) using measures that do not require a physician’s prescription or intervention (e.g., lifestyle modifications) typically outside of formal, institutionally based care mechanisms like physicians’ offices or hospitals in the U.S.A.. or through the NHS in the U.K.. Instead, informal care is provided in places such as homes and communities by lay people or those who are not credentialed as Western trained allopathic or osteopathic medical practitioners.

Other terms and scopes of practices that can be considered within the rubric of “informal care” are “alternative medicine”, “complementary medicine”, and “unconventional health care practices”. Specific types of “informal care” include, but are not limited to: Ayurvedic medicine, body/mind medicine (including biofeedback, imagery, and yoga), chiropractic, exercise, herbal medicine, Native Hawaiian La‘au Lapa‘au, self-care, prayer, and traditional Chinese or Oriental medicine (including acupuncture and moxibustion).

“Racial/ethnic minority communities” are defined as those people (or populations) who constitute less than the numerical majority of that nation’s population. In the United States, the racial/ethnic populations as defined by the Federal Government’s Office of Management and Budget Directive number 15 are as follows: 1. White (currently, the majority population); 2. Black (or African American); 3. Hispanic (not a racial category, but an ethnic category, since Hispanics can be of any race); 4. Asian or Pacific Islander; and 5. American Indian and Alaska Native. These populations are identified through self-report from the latest (1990) Census.

In the U.K., black and ethnic populations consists of (Asian) Indians, Pakistani, Bangladeshi, Black African, Black Caribbean, Black-Other, Chinese, Other Asians, and other (NHS, 1995). However, these U.K. statistics are classified in terms of country of birth rather than self-identified racial or ethnic categorizations as used in the U.S.A. Hence, for the U.K., the delineations are based upon countries of birth regardless of self-identified racial/ethnic classifications. Black and ethnic minorities born in the U.K. would not be reflected in their ancestral countries of origin. Informal care can be the vehicle for empowering minority communities to pursue culturally appropriate health care for their respective peoples. Therefore, understanding informal care and the historical background and social context for empowerment by minorities is important*.*

B. Why the issue is important and relevant to the health of all people, and especially to racial/ethnic minorities .

Informal care is important and relevant to the health of all people because informal care can maintain health, prevent disease, and promote health in perhaps more culturally acceptable and more cost-effective means than formal care. Included in informal care are such lifestyle modifications such as, choosing not to use tobacco, dietary modifications, exercising, etc., the application of which may prevent approximately fifty percent of all avoidable, premature deaths (U.S. DHHS, 1979). These lifestyle choices and practices are cost-effective; they do not require the use of formal care, and in deed in the words of Joseph Califano, former Secretary of Health, Education, and Welfare, “could do more than doctors..” (U.S. DHHS, 1979). Thus, the potential of optimal health is a promise open to all if informal care can be properly exercised.

Informal care in the form of traditional medicine is used by 80 per cent of the world’s population, according to the World Health Organization (Marti and Hine, 1995). Twenty five percent of pharmaceutical drugs are derived from plants or herbs.

Informal care may be used more frequently among racial/ethnic minorities because of their long standing cultural and traditional significance and also because barriers to accessing formal care may be more prevalent among racial/ethnic minorities. Barriers to accessing formal care may include cultural, financial, geographic (transportation), organizational, and linguistic barriers. Hence, informal care may be the only reliable care that racial/ethnic minorities receive. However, a valid documentation on the prevalence of informal care practices within any community is difficult because of the broadness of its scope and the logistical barriers in conducting such surveys in racial/ethnic communities.

“*Empowerment*” is defined as the right for people to determine their own destinies. Two important reasons for the empowerment of racial/ethnic minority communities are: (1.) demographic factors and (2) the historical legacy. In terms of demographic factors, racial/ethnic minorities in the U.S.A. are growing at a pace faster than the majority population. For example, based upon the 1990 Census, each of the U.S.A.’s racial/ethnic minority populations grew proportionally faster than the majority population (U.S. Department of Commerce, 1991). Hawaii is already a state without a majority for any single ethnic group; the most populous state, California is fast becoming likewise. By 2050, the U.S.A.’s current minorities may be the majority population. Hence, interest in empowerment for today’s racial/ethnic minorities to improve their health status is an investment in the future and is in the national interest since the health of minority Americans may very well be the health status of majority Americans in the Twenty-first

Century.

In the U.K., black and ethnic populations constitute six per cent or an estimated three million people in England and Wales (NHS, 1995). Their patterns of morbidity and mortality differ from White majority population and the within-black and ethnic populations differences are also quite prominent.

The second reason is the historical legacy. The right for population-specific destiny has not always existed in the history of the United States. Each of the racial minorities in the United States has experienced at least one or more historical instances of the legal or deliberate denial of authorization to determine one's destiny. In the United Kingdom, almost every minority population can trace its relationship to the U.K. to a colonial experience such as those of Indian, Pakistani, or Bangladeshian origin to the British colonization of India, Blacks due to British colonization of Nigeria and Kenya in Africa and Jamaica in the West Indies, or Chinese due to the British colonization of Hong Kong.

Empowering minority communities through informal care may be the most culturally appropriate approach for improving the health status of minority populations. Informal care is pervasively used by minorities and its potential in improving the health of minorities has been under-estimated and under-utilized.

II. STRATEGIES USED

A. In the past and present

Informal care is as old as motherhood. Mothers have been practicing informal care centuries before the advent of formal care. In fact, the majority of normal growth and development skills needed for healthy beginnings are taught by mothers in their homes. For instance, the skills of eating properly, the importance of sleep, toilet training, oral and personal hygiene, proper mental attitudes, respect for self and for others, care for “minor” illnesses are all taught, modeled, and practiced within particular culturally acceptable contexts in the home by mothers. Informal care for infant and childhood aches and illnesses are typically resorted to as the first measures undertaken by parents. In some instances, the informal care practiced, e.g., “coining” may not be understood or accepted by formal care practitioners or their institutions (Munoz, 1995). These types of informal care persist.

Specific minority populations in the U.S.A. have their own informal care delivery systems. Perhaps the oldest and best known is the informal care delivered by the American medicine people. These traditional healers teach the necessity of harmony of the physical with the mental and spiritual if health and wholeness is to be secured. Traditional American Indian healers perform bedside ceremonies for their patients as well as in other environments (Indian Health Service, 1997). The Indian Health Service has recognized the value of these traditional healers and has established as policy the following:

...to protect and preserve the inherent right of all Native Americans to believe, express and exercise their traditional religions.

> ...to recognize the value and efficacy to traditional beliefs, ceremonies, and practices of the healing of body, mind, and spirit...to encourage a climate of respect and acceptance in which an individual's private traditional beliefs become a part of the healing and

harmonizing force within his/her life.

...The goal is that there be respect and complimentary interface between the two systems of medicine and religion. Care must be taken that apparent Indian Health Service and federal beneficence does not become a means of destroying a system of healing which has both a long history and contemporary relevance.

This policy was signed by Emery A. Johnson, M.D., Director, Indian Health Service.

The above policy was re-affirmed and strengthened in 1994 by Michael H. Trujillo, M.D., M.P.H., Director, Indian Health Service as follows:

...It is the policy of the IHS to facilitate access to traditional medicine practices, thereby protecting the right of American Indian and Alaska Native people to their beliefs and health practices as defined by the tribe's or village's traditional culture. This policy is meant to complement and support previously stated IHS policy for implementing the American Indian Religious Freedom Act of 1978 (Public Law 95-341, as amended).

This IHS policy is expressed in space that has been customized to traditional Native American medical practices such as a "Medicine Wheel" room in the Billings, MT Area IHS Hospital and the "Ritual" room at the Albuquerque IHS Hospital.

Native Hawaiian health practices are supported through the Native Hawaiian Program operated through funding by the Health Services and Resources Administration's Bureau of Primary Health Care. Quarterly reports to the Bureau report on the provision of Native Hawaiian health practices.

Continuing such indigenous health practices is important because much has been lost over time. For example, in the early history of the United States, particularly during its westward expansion, the more powerful and ambitious White settlers to the United States forcibly removed American Indians from their lands on several occasions. The story of the Indian Chief Tecumseh's efforts to regain his people's lands and destiny led to historians calling Tecumseh's efforts as a "Trail of Tears".

The first African Americans were brought to the United States as slaves; they were treated as property without any human rights. Their emancipation came about only after the U.S. Civil War, approximately one century ago. However, even as late as the 1970's, African Americans were judged frequently by the color of their skin, rather than the content of their character. The late Martin Luther King, Jr.'s efforts were instrumental in bringing about many long-needed changes in civil rights.

Asian Americans came here willingly. However, they were later specifically excluded. The Chinese Exclusion Act of 1882, the Gentlemen's Agreement of 1908, and the National Origins Act of 1924 all prohibited Chinese and Japanese immigration, while allowing the annual entry of thousands of European immigrants. It was only in 1965 that the U.S. Congress fully lifted barriers to immigration on the basis of national quotas.

Additionally, between 1941 and 1946, 120,000 Japanese Americans were denied their civil rights and forcibly moved from Hawaii and the West Coast to be interned in Wyoming, just because they were of Japanese origin. By contrast, German or Italian Americans, who were also originally from the U.S.'s enemies in World War II, were never moved.

Only in 1993 did the U.S. Congress formally apologize to Native Hawaiians for forcibly overthrowing their duly sovereign Queen (Public Law 103-150) more than 150 years ago. Prior to that unlawful overthrow, indigenous Hawaiians were an independent people.

The British “imported” many black and ethnic peoples to the U.K. from their colonies in the early part of the twentieth century to augment the British workforce, primarily for “blue collar” jobs. Later, Britain became a desirable destination for Commonwealth residents of color to advance their employment prospects in their homes in Africa, the Caribbean, or Hong Kong by earning diplomas from British universities. Those with diplomas from U.K. institutions were given better jobs in their lands of origin if those countries or colonies were part of the Commonwealth. However, Chinese from the British Crown Colony of Hong Kong were considered “British subjects” but did not the rights of other Britons born in the U.K. (such as the right to vote). In fact, the U.K. did not participate in any examination of a human rights record for Hong Kong until shortly before the U.K. was to hand over its eastern-most colony to the People’s Republic of China in 1997.

B. Broadly as a Nation

In 1990, a Harvard University-led investigation team (Eisenberg, Kessler, Foster, et al., 1993) surveyed the prevalence, costs, and patterns of unconventional medicine use in the U.S.A. They conducted the English language-only telephone survey for in a national sample of adults comparable in composition to the 1989 U.S. National Health Interview Survey, but their sample under-represented minorities in comparison to the 1990 Census: (Blacks: sample, 9% versus 12.5% in U.S.A.; Hispanics, sample, 6% versus 9% in U.S.A.; Asian: sample, 1% versus 3% in U.S.A.; American Indian/Alaska Native, sample, none versus 1% in U.S.A.) . In spite of these survey methodology limitations that under-estimated U.S. racial/ethnic minorities who may have been excluded in survey participation due to not having a telephone or their being not fluent in English, interesting data emerged. These data reflect an under-estimation of unconventional medicine use because of the above mentioned survey methodology limitations.

According to this investigative team, an estimated 61 million (or one in three) American adults used some form of unconventional medical therapy (Eisenberg, Kessler, Foster, et al., 1993). The use of unconventional therapy was not related to gender or insurance status, but was more common among those aged 25 to 49 than to those older or younger. Based upon their survey methodology, the use of unconventional therapy was significantly less common among Blacks (23 per cent) compared to other racial groups (35 per cent, $p<.05$) and was significantly more common in the western part of the U.S.A. than other parts of the country. Approximately 22 million Americans saw providers of unconventional therapy for a principal medical condition even though they were not reimbursed by a health insurance company in the majority of instances. In 70 per cent of the cases, formal care providers are not informed by their patients that they are engaged in unconventional therapy (Eisenberg, Kessler, Foster, et al., 1993).

The most frequently reported medical conditions for the use of unconventional therapy were for back problems (20 per cent), allergies and arthritis (16 per cent each), insomnia (14 per cent), sprains or strains and headaches (13 per cent each). An estimated 425 million visits to providers of unconventional therapists were made. The magnitude of these visits to informal care providers exceeded the estimated 388 million visits to all primary (formal) care physicians combined (Schappert, 1992).

In terms of dollars, the projected amount spent on unconventional therapy and care,

$13.7 billion, exceeded the amount paid by Americans for all hospitalizations ($12.8 billion). Thus, considering the magnitude of the usage of unconventional medicine, visits to informal care providers, and the dollar value of unconventional therapies, Americans are major consumers of informal care. The data collected by the previously mentioned Harvard team suggest that if one third of adult Americans participate in unconventional medical care, then the proportion of racial/ethnic minority Americans who participate in unconventional medicine may be as high as one-half.

Data on the use of informal care among minorities are exceedingly difficult to obtain. Use of informal care (particularly Oriental traditional medicine) by Asian Americans is very common but difficult to quantify. Likewise, data on Hispanic use of the *curandero* or traditional healer are likewise unavailable. Despite pervasive use among IHS clinics, data on use of Native American traditional medicines could not be obtained.

Data to support that minorities may use unconventional medicine and informal care in proportionally greater amounts may also be surmised by a study of patients being treated for HIV infection and AIDS. AIDS occur proportionally more frequently among racial/ethnic minorities than the majority American population. Over 100 alternative therapies have been used by AIDS patients (Hand, 1989). In another Harvard University-led study, investigators reported that forty percent of AIDS patients used alternative or complementary therapies (Anderson, O'Connor, MacGregor, Schwartz, 1993) in a sample that consisted of 65 per cent racial/ethnic minorities. Patients using alternative therapies were just as satisfied or often more satisfied with alternative therapies compared to conventional (formal care) therapies (Anderson, O'Connor, MacGregor, Schwartz, 1993).

To exacerbate the data deficiencies, no national mechanism exists to determine the prevalence of informal care by minorities. No objectives relate to traditional medicine in national health plans and the U.S.A. has had a very short history with respect to health goals and objectives. The first national health goals and objectives, *Healthy People* (U.S. DHHS, 1979) and the *1990 Health Objectives for the Nation* for the U.S.A. were published in 1979 for attainment in 1990. At the approximate mid-point towards the 1990 Objectives, then Secretary of Health and Human Services, Margaret Heckler commissioned a departmental study to examine the health status of Black and minority Americans. The 1985 *Secretary's Task Force Report on Black and Minority Health* resulted, documenting health disparities between the majority and minority populations. The *Report* concluded that 60,000 excess deaths could be attributed to these health gaps. Five diseases or risk factors for which minority populations experienced proportionally higher rates than their White counterparts (U.S. DHHS, 1985) were identified. These diseases or risk factors were as follows: cardiovascular disease, cancer, diabetes, chemical dependency, substance abuse, and homicide. Later, HIV/AIDS was added to this list of conditions in which minority populations experienced health status disparities. Hence, U.S. minority populations have had a historical legacy of dis-empowerment. Efforts to change the legacy are recent and incomplete.

In the U.K., Government efforts to improve the health of minority populations began in the 1980s. First, the U.K. Government launched the national "Stop Rickets Campaign" in 1981 to alert the Asian community and health professionals on the prevalence of rickets and the importance of overcoming vitamin D deficiencies. This one-and one-half year campaign revealed the need to overcome linguistic and cultural barriers in service delivery. In 1984-87, the U.K. Government initiated the "Asian Mother and Baby Campaign". "Link" (outreach) workers from the targeted communities were appointed to overcome linguistic and cultural barriers. This campaign revealed the need for the development of appropriate health policies. In 1988, black and ethnic minority health was included in the Department of Health's management review of health service performance. In 1991, a question on ethnic origin was included in the 1991 Census for the first time. In March, 1994, the NHS Ethnic Health Unit was established to secure more effective care within the NHS for minority populations (Hopkins & Bahl, 1993; Balarajan & Raleigh, 1993)..

Targets for five sections: coronary heart disease and stroke; cancers; mental illness; HIV/AIDS and sexual health; and accidents, were articulated in *Health of the Nation* (HSMO, 1992), the equivalent to the U.S.A.'s *Healthy People* (U.S. DHHS, 1979). In many instances such as coronary heart disease and stroke, diabetes, infant health, inherited blood disorders, and access to health services, those born outside of the U.K. experience disproportionally more deaths than those born in the U.K. However, no objectives specifically identified minority populations as the target populations for these objectives in the same way that racially ethnic objectives were articulated in *Healthy People 2000* (U.S. DHHS, 1991).

C. Encompassing minority health professionals and cultural competency

Minority formal care health professionals are more likely to be aware of and supportive of informal care practices associated with their own racial/ethnic group. Minority health professionals are also more likely to serve minority patients.

Cultural competence is also more likely to be characteristic of those minority health professionals who are aware of and supportive of informal care practices. Cultural competence has three components: purpose, attitude, and skills. The purpose of cultural competency is to achieve improved health outcomes. Attitude is the willingness to adapt oneself to others' needs. Proper attitudes must come from within the professional, but it may be promoted through increased knowledge of others' backgrounds and the deliberate transpositions of roles and perspectives. Skills are those competencies or behaviors that exemplify correctness of technique in interactions between the professional and the patient.

Minority health professionals are individuals most likely to be the impetus to empower their own communities for health improvement. Hence, increasing the number of trained minority health professionals is one strategy that must be pursued. They are the ones most like targeted racial/ethnic communities who need to be targeted for their disparate health status.

In analyzing the empowerment of ethnic minorities in human service organizations, Gutierrez discussed appreciating and understanding diversity of minority clients, rather than just considering their human services needs. She outlined the following steps for ethnic sensitive services: 1. Developing access to services (e.g., engaging bi-lingual, bi-cultural staff); 2. Tailoring interventions (e.g., through learning others' culture); 3. Modifying services (e.g., integrating traditional medicine with formal, Western medicine); 4. Initiating an appropriate organization development model and a specialized program model (e.g., initiating a Native Hawaiian health care system) (Hasenfeld, 1992).

Another model, by Arthur Himmelman, discusses empowerment in a continuum of collaboration strategies (Himmelman, 1994). Himmelman indicates that the continuum of collaboration is differentiated by the degree to which three barriers: time, trust, and turf can be overcome. In the first stage, networking is defined as exchanging information for mutual benefit. While networking reflects initial trust, commitments of time and sharing of turf are limited. The next stage, coordinating, results in exchanging information and altering activities to achieve a common purpose. Mutual investments of time, trust, and turf sharing are increased. The third stage, cooperating requires greater organizational commitments than either networking or coordinating. Next, collaborating, including collaborative empowerment involves considerably more time, trust, and turf commitments. Himmelman defined empowerment as "the capacity to set priorities and control resources that are essential for increasing community self-determination" (Himmelman, 1994). Empowerment so defined includes community organization on the basis of a collaborative purpose and facilitating a process for integrating outside institutions to support that purpose (Himmelman, 1994).

Dr. Pui-Ling Li, the U.K. counterpart presenter in the workshop entitled, "Involving black and minority ethnic users in delivery of services and empowering communities", illustrated how she had empowered the Chinese community in London. First, she compiled demographic data on the Chinese population in the U.K. From an analyses of those data, she indicated that the age group, 20-44 was the largest group; nearly 30 percent were born in the U.K.; but that nearly all older people who were born outside the U.K. did not speak English. Furthermore, only 25 per cent of these older people had education beyond the primary school level. The majority of all Chinese in the U.K. is in the food catering trade. Since most are engaged in the catering trade, she documented that access to health care meant accommodating the schedules of those who worked 12 or more hours per day nearly every day of the week. A comfortable and convenient social setting in London's Chinatown where all workers spoke Cantonese was very important. She therefore founded the London Chinese Health Resource Centre as a means of empowering the Chinese community to meet its own needs. This Centre not only provides linguistically and culturally competent services, but also English lessons are offered to further empower the Chinese. In so doing, the London Chinese Health Resource Centre has become an identifiable organization to coordinate the work of the Chinese in London and create a focus. It is rooted in the community and is forming an infrastructure to influence the district and national levels of health policy (Li, 1997).

D. Inclusively for all people

As suggested by survey data (Eisenberg, Kessler, Foster, et al., 1993), informal care may be practiced more frequently and more commonly than formal care. Informal care may be used to supplement formal care and may not be reported to formal care providers. Achieving change requires both individual, social, and political change.

At the individual and social levels in both the U.S.A. and the U.K., overcoming linguistic and cultural barriers to health services is fundamental. With respect to overcoming linguistic and cultural barriers in the U.S.A., Chen developed the indigenous model (Chen, 1989) with minority community coalition development and applied it to the provision of heart health services and heart health education for Southeast Asians who typically have had linguistic and cultural barriers to service. They have empirically demonstrated the effectiveness of this model through Office of Minority Health funding (Chen, Zaharlick, Kuun, et al., 1992; Chen, Anderson, Moeschberger, et al., 1994). In the U.K., the Government has translated the Patient's Charter of Rights into numerous languages to communicate the standards of health care that can be expected by all who use the NHS. In democracies such as the U.S.A. and the U.K., the principal means to affect political change is in the ballot box. When people vote, they can decide their destiny. Many stories have been told about the importance of a single vote. However, racial/ethnic minorities, by definition, do not have sufficient votes in their favor unless they work together either collectively or with segments of the majority population to bring about change.

Change occurred in the U.K. Tony Blair and his party won in 1997. This change created the first time that a black Member of Parliament, the Honorable Paul Boateng, became the Under Secretary of State at the Department of Health. Along with Ms. Tessa Jowell, the Minister for Public Health and the British government's Ethnic Health Advisor, Ms. Veena Bahl, prospects for improving the health status and the empowering of minority populations in the U.K. appear promising.

The unfortunate history of minorities in the U.S.A. is that they do not typically exercise their right to vote. For instance, only about one in six Asian Americans votes. Hence, when Asian Americans constitute only 3% of the population, their actual strength is diminished to less than 1% because only 1/6 participates in the voting process.

E. Specifically to address disparities affecting vulnerable populations, especially racial/ethnic populations

The expenses associated with formal care compared with the relatively low cost of informal care as well as the cultural familiarity and flexibility of informal care suggest that informal care should be increasingly utilized by vulnerable populations. Rather than less informal care, more informal care should be encouraged. Informal care that is scientifically supported as efficacious, or at least in which no harm is done, should be used to address disparities in racial/ethnic minorities.

The history of the U.S.A.'s programs to empower minorities is too short to determine whether disparities have been removed. The history of the U.K.'s programs to empower minorities and address minority health issues may even be shorter. However, greater institutionalization of informal care by minorities may provide alternative means to improve the health of racial/ethnic populations.

F. Specifically to address needs of increasingly diverse populations

Both the U.S.A. and U.K. are nations of immigrants and are increasingly becoming more demographically diverse. Based upon the 1990 Census, the only original inhabitants of the U.S.A., American Indians and Alaska Natives, made up approximately one per cent of the population. The remaining 99 per cent in the U.S.A. are all immigrants and refugees or descendants of immigrants and refugees (Lin-Fu, 1994). To build upon the best of all of U.S.A. residents, we must learn from each other. We can benefit from the traditions of informal care from other racial/ethnic populations to meet our needs as well.

As the population becomes increasingly diverse, the issue of empowerment becomes even more complex. Resources become tighter and the competition for resources becomes more intense. Among populations who have resided in the U.S.A. longer, there may be the feeling of why newer populations should receive Federal assistance when older racial/ethnic populations did not receive such assistance**.** In the U.K., tensions may arise from black and ethnic minorities based upon countries of birth since data and presumably resources to address those need may be based upon countries of birth.

III. INITIATIVES

A. Federal

In 1992 the U.S. Congress established the Office of Alternative Medicine (OAM) within the National Institutes of Health (NIH). The mission of this Office is to identify and evaluate unconventional health care practices that maintain or induce healing processes that, in turn, promote wellness and alleviate suffering, illness, and disease. Since its initial budget of U.S.$2 million, the budget grew to $12 million in 1997. The OAM supports and conducts research and research training on unconventional health care practices and disseminates information on their clinical usefulness, scientific validity and theoretical underpinnings.

The OAM classifies its alternative medicine categories into 1. Diet nutrition/lifestyle changes; 2. Mind body control; 3. Herbal medicine; 4. Manual healing; 5. Pharmacological and biological treatments; 6. Bioelectromagnetic applications; and 7. Alternative systems. The OAM has awarded grants to study such subjects as acupuncture, Ayurvedic medicine, biofeedback and relaxation, energetic therapy, homeopathy, hypnosis, imagery and relaxation, massage therapy, and qi gong.

In direct response to the 1985 Secretary’s Task Force on Black and Minority Health, the Office of Minority Health was created by Executive Order and placed as an office within the Office of the Secretary of Health and Human Services (equivalent to the U.K.’s National Health Service Office). After being created by Executive Order, the Office of Minority Health operating under the Secretary of Health and Human Services, initiated various grants programs designed to demonstrate efficacy of addressing risk factors in minority communities. To disseminate its influence, Federal agencies within the U.S. Public Health Service were asked to establish their own office of minority health. The intent of such measures were not for those agency offices to be “cop-outs” for doing that agency’s work in minority health; rather, they were to be that agency’s “conscience”. Further grant making funding authority was given to the Federal Office of Minority Health. In 1990, the Disadvantaged Minority Health Act was passed by the Congress that resulted in the establishment of the Office by statute.

Beginning in 1993, the Office of Minority Health began a series of departmental initiatives for each of the U.S.A.’s racial/ethnic populations. The first Initiative established was targeted at Historically Black Colleges and Universities (1993). This was followed in 1996 with the implementation of the nine-point Hispanic Agenda for Action and in 1996 with the Tribal Colleges and Universities Initiative for American Indians and Alaska Native people. On June 26, 1997, the Department announced that it launched its own Asian American and Pacific Islander Initiative to address the health and human services needs of this population.

The NHS Ethnic Health Unit in England was established only in March 1994. This Unit attempts to secure more effective care within the NHS for minorities by encouraging the NHS to form partnerships with minority groups. The Unit also works to improve appropriate and sensitive services. Both of these activities have been funded at approximately one million pounds sterling (U.S.$1.6 million) per year. The Unit also collaborates with a variety of organizations such as the Health Education Authority, King's Fund, Commission for Racial Equality and the National Association of Health Authorities and Trusts, and national voluntary organizations. Additionally, Professor R. Balarajan and Dr. Soni Raleigh of the Institute of Public Health at the University of Surrey have collaborated to produce several epidemiological analyses of health patterns affecting minority populations in the U.K. (HMSO, 1995). The NHS Ethnic Health Unit initiated the 1997 bi-national conference, "Health Gain for Black and Minority Ethnic Communities"; in so doing, both the U.K. and the U.S.A. can benefit from sharing solutions to common problems.

B. State and Local

No known research or activities are being conducted by state or local governments in informal care. In response to a national awakening in the U.S.A. to meeting the needs of racial/ethnic populations, states began to establish offices of minority health. The first state to do this was the State of Ohio establishing the Ohio Commission on Minority Health. Subsequently, other states have formed similar entities.

In the U.K., the NHS Ethnic Unit collaborates with "Regional Offices of the NHS in their performance management, research and development and public health functions to ensure that ethnic health issues are an important part of purchasing health services" (HSMO, 1995).

IV. STRENGTHS/WEAKNESSES/EFFECTIVENESS/INEFFECTIVENESS

Informal care is a two-edged sword. Its strengths lie in its simplicity and convenience. Informal care may be used at any time and place. Informal care places the consumer (or patient) in control, empowering the individual to choose what s/he wants rather than being told by a formal care provider as to what must be done. The effectiveness of informal care is typically qualitative and is subjectively-based.

Weaknesses for informal care typically lie in the absence of quantitatively-based "scientifically" determined efficacy. Data on the numbers, rates, and probabilities of effectiveness are frequently missing. Consumers can be overwhelmed by the choices presented by informal care and may find choosing informal care options difficult. In many cases, consumers may only be guided by their instincts and may be persuaded by individual testimonies all without a sufficient "scientific" base to guide decision-making.

Hence, the position of the NIH's OAM Complementary and Alternative Medicine (CAM) Ad Hoc Panel is instructive in weighing the strengths/effectiveness and weaknesses/ineffectiveness of CAM for HIV. In summary, the Panel cited four reasons for focusing attention on CAM for HIV:

1. The use of CAM by HIV-infected individuals is on the increase.
2. CAM therapies may be potentially effective, by themselves or in combination with conventional therapies (formal care).
3. CAM may cause potential harm by themselves or in combination with conventional therapies (formal care).
4. Perceptions on CAM therapies could affect the HIV-infected individual's views toward conventional (formal care).

Empowerment for minority communities should be considered a right, not a privilege. In democracies, there are dual commitments. On the one hand, there is the principle of "one person, one vote". On the other hand, there is the principle of providing a "safety net: helping those who need help". Empowerment for minority communities should be considered as securing what one deserves. Everyone deserves the right to health. In the words of the U.K. Minister for Public Health, Tessa Jowell, "Early death is the ultimate social exclusion."

The inherent weakness of any movement to empower minorities is the need for all to work together on a common agenda. Without agreement and speaking with one voice, there can be no real empowerment, especially for minorities. In the words of the Honorable Paul Boateng, the U.K. Under Secretary of State for Health, "We are strongest when we are united."

V. WHERE WE ARE MOST LIKELY TO GO v.s. WHERE WE NEED TO GO

The direction where we are most likely to go in the area of informal care is where the people are already going. With increasing medical care costs and with frustration with Western medical care institutions, more and more people are seeking informal care. The trend is such that formally trained Western health professionals must acknowledge their patients' use of informal care. Physicians are being advised to inquire as to their patients' use of informal care. .

However, our aim should really be to eliminate racial/ethnic differences in health status in both the U.S.A. and the U.K.. This, in fact, is a proposed goal for the U.S.A.'s Year 2010 Health Objectives for the Nation. The level of health status that can be achieved for the majority should be attainable by all, regardless of racial/ethnic background. Specific recommendations follow.

VI. RECOMMENDATIONS

1. Operationally define various aspects of informal care, e.g., different forms of CAM so that surveys on the uses of various forms of informal care and CAM can be documented in both the U.S.A. and the U.K..

2. Conduct surveys to document the prevalence and patterns of informal care usage among racial/ethnic populations in both the U.S.A. and the U.K. Such surveys should be conducted in such a way to overcome barriers associated with participation in previously conducted surveys, e.g., conducting surveys fact-to-face, engaging racial/ethnic members of the surveyed communities to overcome cultural and linguistic barriers to

survey participation, using concepts and not just literal translations (Boyce, 1995), etc.

3. Identify cases where healthful outcomes occurred exclusively through informal care practices. Conduct case studies and case-control studies to assess factors associated with the efficacy of such practices in both the U.S.A. and the U.K.

4. Conduct scientifically rigorous, controlled studies to assess the efficacy of specific informal care practices in both the U.S.A. and the U.K..

5. Encourage cross-training of formal care practitioners with informal care practitioners and formalize dialogue, training, and research activities that would include parity in participation in both the U.S.A. and the U.K..

6. Collect both U.S.A. and U.K. data (including oral histories and literature searches) of successful cases of empowerment in minority communities. Identify factors associated with their success including the role of their cultures and their adaptation to their environments that enabled their success.

7. Earn trust from individuals and organizations. Network, coordinate, cooperate, and collaborate for empowerment.

8. Commission selected U.S.A. and U.K. investigators to present their findings and recommendations from the above seven recommendations at the next bi-national conference and build upon the Joint Statement of Intent of the Department of Health of the United Kingdom and the Department of Health and Human Services of the United States of American on “Collaboration in Minority Ethnic Health” signed in London in September, 1997 between the Secretary of State for the U.K. and the Deputy Secretary of Health and Human Services for the U.S.A.

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y. respective countries. In this paper, the term, “minority” will be used.